
Terri Schiavo: Unsettling The Settled

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I. INTRODUCTION

In the early months of 2005, Terri Schiavo's story captured the national public spotlight in ways reminiscent of Karen Ann Quinlan in the 1970s and Nancy Beth Cruzan in the 1980s. All were young women whose lives were tragically altered by traumatic events that left them in what we now call a permanent vegetative state.¹ Their fates were

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1. In 1972, two doctors adopted the term "persistent vegetative state" to describe patients who had entered a continuing state of unconsciousness marked by periods of wakefulness. Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, LANCET, Apr. 1972, at 734-37. Since then, those both inside and outside the medical community have adopted the term, but it has come to denote a permanent rather than merely a continuing or persistent condition. BRYAN JENNETT, *THE VEGETATIVE STATE: MEDICAL FACTS, ETHICAL AND LEGAL DILEMMAS* 4-5 (2002). The term "permanent vegetative state" more accurately describes the condition and may be gaining ground, although a number of statutes that refer to the vegetative state in its permanent condition still use the term "persistent vegetative state." See, e.g., FLA. STAT. § 765.101(12) (2004) (defining "persistent vegetative state" as "a permanent and irreversible condition of unconsciousness in which there is: (a) The absence of voluntary action or cognitive behavior of any kind. (b) An inability to communicate or interact purposefully with the environment."). In this paper, I use the term "permanent vegetative state" to refer to the condition at issue, which is the variant of vegetativeness that is considered irreversible. It should be noted that a number of commentators have protested the use of the term "vegetative" as demeaning because of its suggestion that the patient is something less than a person, a mere "vegetable." See, e.g., Raphael Cohen-Almagor, *Some Observations on Post-Coma Unawareness Patients and on Other Forms of Unconscious Patients: Policy Proposals*, 16 MED. & L. 451, 461 (1997) ("[T]he term 'vegetative' dehumanizes the patients, suggesting that we speak of some form of sub-human life."); Adam J. Hildebrand, *Masked Intentions: The Masquerade of Killing Thoughts Used to Justify Dehydrating and Starving People in a "Persistent Vegetative State" and People with Other Profound Neurological Impairments*, 16 ISSUES L. & MED. 143, 149 (2000) (arguing that the term is "an insult to the inherent dignity of the human person"). While I am sympathetic to this argument, the terminology has become so widespread that using a different term may cause confusion, because no alternative has yet achieved significant use.

publicly and vigorously debated in court and in the media.² The controversies surrounding *Quinlan* and *Cruzan* generated landmark court rulings,³ but the legacy of the Schiavo controversy is still unclear.

The Schiavo controversy did not significantly further or change end-of-life decision-making law, at least not in immediate or obvious ways. Although Terri Schiavo's parents, Mary and Robert Schindler, fought

2. See JOSEPH & JULIA QUINLAN WITH PHYLLIS BATTELLE, *KAREN ANN: THE QUINLANS TELL THEIR STORY* (1977) (describing throughout the book the media and public interest over the fate of Karen Ann Quinlan); WILLIAM H. COLBY, *LONG GOODBYE: THE DEATHS OF NANCY CRUZAN* (2002) (describing throughout the book the media and public interest in the *Cruzan* case); Sheryl Gay Stolberg, *Schiavo's Legacy: A National Debate; Ethics, Medicine and Politics Collide*, INT'L HERALD TRIB., Apr. 1, 2005, News, at 1 ("The life and death of Terri Schiavo intensely public, highly polarizing and played out around the clock on the Internet and television has become a touchstone in American culture.").

3. In *In re Quinlan*, 355 A.2d 647 (N.J.), cert. denied, 429 U.S. 922 (1976), the New Jersey Supreme Court, in a case of first impression, held that Karen Quinlan had a federal constitutional right to privacy to terminate life-sustaining treatment and that Quinlan's father could act on his daughter's behalf to order removal of the ventilator that aided her respiration. In *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990), the U.S. Supreme Court, while upholding Missouri's requirement that Cruzan's feeding tube could not be removed absent clear and convincing evidence that she would want it removed, stated that a constitutional right to refuse life-sustaining medical treatment could be inferred from the Court's prior decisions. *Id.* at 278. Many have interpreted *Cruzan* to establish a constitutional "right to die," if not with assistance, then by withdrawal of unwanted treatment. See *In re Browning*, 568 So. 2d 4, 10 (Fla. 1990) (citing *Cruzan* for the proposition that, "[a] competent individual has the constitutional right to refuse medical treatment regardless of his or her medical condition"); BARRY R. FURROW ET AL., *HEALTH LAW: CASES, MATERIALS AND PROBLEMS* 1359 (5th ed. 2004) (pointing out that, "Many authoritative sources presumed that the opinion did recognize a constitutionally protected liberty interest in a competent person to refuse unwanted medical treatment. Indeed, . . . the case was hailed by the *New York Times* as the first to recognize a right to die."). *Cruzan* is also cited for the proposition that artificial nutrition and hydration should be considered like other medical treatments that can be withheld or withdrawn according to a patient's wishes, a principle that state courts have uniformly adopted since the *Cruzan* case. See, e.g., *Browning*, 568 So. 2d at 11 (citing *Cruzan* and numerous other court decisions in support of its statement that "Courts overwhelmingly have held that a person may refuse or remove artificial life-support, whether supplying oxygen by a mechanical respirator or supplying food and water through a feeding tube."); MARK H. HALL ET AL., *HEALTH CARE LAW AND ETHICS* 507 (6th ed. 2003) ("The *Cruzan* case essentially resolved the debate [whether artificial nutrition and hydration could be discontinued] in terms of the law, and now it is widely accepted that patients can refuse any medical treatment."); JANET L. DOLGIN & LOIS L. SHEPHERD, *BIOETHICS AND THE LAW* 745 (2005) ("As the law in this area has evolved, and as represented by the opinion in *Cruzan*, artificially provided nutrition and hydration have come to be regarded in many jurisdictions in the same way as artificial ventilation."). It is important to note, however, as other commentators have, see, for example FURROW, *supra*; HALL, *supra*; DOLGIN & SHEPHERD, *supra*, that the majority opinion in *Cruzan* states that the right to refuse unwanted treatment may be inferred from prior decisions of the Court, but does not explicitly recognize such a right. In fact, scholars Alan Meisel and Kathy L. Cerminara state that "*Cruzan* has . . . had virtually no effect on the case law." ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISION MAKING* § 6.03[G] [4][b] (3d ed. 2005). Meisel and Cerminara also, however, note that following *Cruzan* a number of state legislatures moved to loosen restrictions on the removal of artificial nutrition and hydration. *Id.*

against the removal of their daughter's feeding tube with just about every conceivable legal argument and exhausted every conceivable avenue of relief, appealing to all three branches of government at both state and federal levels and also offering private settlement, they ultimately failed. Circuit Court Judge Greer's original order in February 2000 that Terri Schiavo's feeding tube should be removed in accordance with Florida law ultimately withstood attack.⁴ Michael Schiavo, Terri Schiavo's husband, presented evidence that Terri Schiavo would not want to continue living in a permanent vegetative state by means of a feeding tube and thus convinced Judge Greer that removal of the feeding tube was proper. Even in the face of legislative and executive insistence, other courts, both at the state appellate level and the federal level, refused to undo that determination.⁵ Thirteen days after the third and final removal of her feeding tube, Terri Schiavo died on March 31, 2005.⁶

Cases such as *Quinlan* and *Cruzan* remain good law following the Schiavo controversy, as do the many others that have established the constitutional and common law rights of an incompetent individual to withdraw life-sustaining treatment, including the right to withdraw artificial nutrition and hydration.⁷ Likewise, Florida's statutory apparatus for making decisions to withdraw life-sustaining treatment, developed in the wake of *Quinlan*, *Cruzan*, and similar Florida cases, remains intact. Though the Schiavo controversy did not create any broad new pronouncements of law or produce lasting legislation, it did unsettle a number of legal and ethical issues that might have previously appeared settled.

4. *In re Schiavo*, No. 90-2908GD-003, 2000 WL 34546715 (Fla. Cir. Ct. Feb. 11, 2000) (order allowing the removal of Terri Schiavo's feeding tube pursuant to Florida statute and Michael Schiavo's directions as Terri Schiavo's proxy), available at <http://www.miami.edu/ethics/schiavo/021100-Trial Ct Order 200200.pdf> [hereinafter *Schiavo Original 2000 Order*]; see also *infra* Part II (detailing the development of the *Schiavo* case including the fact that the feeding tube was ultimately removed).

5. See *infra* notes 49–84 (discussing the appellate history of the *Schiavo* case).

6. See *Schiavo Case Resources*, <http://www.miami.edu/ethics/schiavo/timeline.htm> (last visited Jan. 6, 2006) (providing a timeline of Terri Schiavo's life).

7. See, e.g., *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987) (finding the right to refuse medical treatment, including artificial nutrition and hydration, is protected under United States Constitution, Arizona Constitution, and common law right to be free from bodily invasion); *Barber v. Superior Court*, 195 Cal. Rptr. 484, 486 (Cal. Ct. App. 1983) (allowing, in the first reported case, withdrawal of nutrition and hydration; doctors not criminally liable for following family's wishes to discontinue artificial nutrition and hydration from man in "a deeply comatose state from which he was not likely to recover."); *In re Browning*, 568 So. 2d 4 (Fla. 1990) (holding that the constitutional right of privacy embraces the right to refuse all artificial means of life-support).

End-of-life decision-making law appeared almost quiet before the *Schiavo* case. Commentators and activists in this field had moved on to issues of physician-assisted suicide, palliative care, and suits for wrongful living.⁸ Change, however, may be forthcoming, based on the number and intensity of challenges that the Schindlers and their supporters leveled at that law, both as it exists on the books and as it was applied in the *Schiavo* case.⁹ While the *Schiavo* case was pending, Florida considered (but did not pass) legislation that would have made it much more difficult to withdraw artificial nutrition and hydration than other forms of medical treatment.¹⁰ Influenced by the *Schiavo* case, other states also have recently considered legislation to change their standards for withdrawing treatment from incompetent individuals.¹¹

Even if the statutory law remains largely unchanged, will courts, proxies, physicians, and hospitals make decisions about end-of-life treatment in different ways because of what happened in the *Schiavo* case? For example, will courts insist on more definitive evidence of patients' wishes before allowing treatment withdrawal? Will health care providers insist more often that family member surrogates get a court order before removing feeding tubes? Will more proxies or family members challenge the diagnosis of permanent vegetative state? And what will the future hold with respect to government involvement in these cases? Will state governors more often direct those who protect individuals with disabilities to protest family decisions to withdraw treatment?

8. See, for example Symposium, *Physician-Assisted Suicide: Facing Death After Glucksberg and Quill*, 82 MINN. L. REV. 885 (1998); *A Symposium on Physician-Assisted Suicide*, 35 DUQ. L. REV. 1 (1996); *Books: Review Symposium on Euthanasia and Physician-Assisted Suicide*, 25 J. HEALTH POL. POL'Y & L. 377 (2000) for articles related to euthanasia. See, for example, Symposium, *Appropriate Management of Pain: Addressing the Clinical, Legal, and Regulatory Barriers*, 24 J.L. MED. & ETHICS 285 (1996); Symposium, *Legal and Regulatory Issues in Pain Management*, 26 J.L. MED. & ETHICS 265 (1998); Symposium, *The Undertreatment of Pain—Legal, Regulatory and Research Perspectives and Solutions*, 29 J.L. MED. & ETHICS 11 (2001) for numerous articles on pain and comfort. See, for example, Adam M. Milani, *Better Off Dead than Disabled? Should Courts Recognize a "Wrongful Living" Cause of Action when Doctors Fail to Honor Patients' Advance Directives?*, 54 WASH. & LEE L. REV. 149 (1997); S. Elizabeth Wilborn, *The Right to Refuse Medical Treatment; Where There is a Right, There Ought to be a Remedy*, 25 N. KY. L. REV. 649 (1998) for articles discussing wrongful living suits and a cause of action for violation of a patient's right to chose to forego medical treatment. See generally, Compassion & Choices, <http://www.compassionandchoices.org/aboutus/timeline.php> (last visited Jan. 9, 2006) (detailing "MILESTONES in the modern choice in dying movement").

9. See *infra* Part II (describing the various legal and media challenges attempted during the Schiavo controversy).

10. See *infra* notes 61, 71–73 and accompanying text (discussing Florida legislation enacted in response to the Terri Schiavo situation and subsequent legislation proposed in Florida).

11. See *infra* note 155 (listing proposed legislation in various states).

This article provides a brief summary of the facts in the Terri Schiavo controversy.¹² Then it addresses some of the many questions that her case raises.¹³ These questions are clustered around three topics: the role of surrogate decision-making in cases of permanent vegetative state; the relevance of the physical condition of the patient in questions of treatment refusal; and the significance of artificial nutrition and hydration as the kind of treatment refused.

II. FIFTEEN YEARS IN A PERMANENT VEGETATIVE STATE¹⁴

Theresa Marie Schiavo was twenty-seven years old when she suffered cardiac arrest on a February morning in 1990. Her husband of five and a half years, Michael Schiavo, found her in the hallway in their apartment around five a.m. and called 911.¹⁵ Paramedics performed CPR, and after seven attempts at defibrillation, restored her heartbeat.¹⁶ Terri Schiavo was taken to a local hospital and never again regained consciousness.¹⁷

Initially, she entered into a coma.¹⁸ A coma is a temporary state of unconsciousness that resembles sleep, but from which an individual cannot be roused.¹⁹ After some period of time, a patient in a coma will either die without ever recovering consciousness, will recover either complete or partial consciousness, or will enter a vegetative state.²⁰ Terri Schiavo's condition progressed from a coma to a vegetative state. A vegetative state is a unique condition in which the individual has no

12. See *infra* Part II (setting forth Terri Schiavo's story and the legal steps taken in reaction to it).

13. See *infra* Part III (discussing three significant questions raised by Terri Schiavo's situation).

14. The following summary of the facts of the Terri Schiavo controversy was compiled from a number of helpful sources. These sources include: the various court documents filed in the case; JAY WOLFSON, GUARDIAN AD LITEM FOR THERESA MARIE SCHIAVO, A REPORT TO GOVERNOR JEB BUSH IN THE MATTER OF THERESA MARIE SCHIAVO (2003), <http://www.miami.edu/ethics2/schiavo/wolfson's%20report.pdf> [hereinafter WOLFSON REPORT]; Joan Didion, *The Case of Theresa Schiavo*, THE NEW YORK REVIEW OF BOOKS, June 9, 2005; Abstract Appeal: The First Web Log Devoted to Florida Law & the Eleventh Circuit Court of Appeals, <http://www.abstractappeal.com/schiavo/infopage.html> (last visited Jan. 6, 2006) (including information regarding the legal circumstances surrounding the Terri Schiavo case); Schiavo Case Resources, *supra* note 6 (providing a timeline of Terri Schiavo's life).

15. Didion, *supra* note 14, at 60.

16. *Id.*

17. Schiavo Original 2000 Order, *supra* note 4, at 2.

18. WOLFSON REPORT, *supra* note 14, at 7.

19. The Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State—First of Two Parts*, 330 NEW ENG. J. MED. 1499, 1501–02 (1994) [hereinafter Task Force Report].

20. *Id.* at 1502 (listing the three possible outcomes for coma patients).

consciousness but is not in a sleeplike state of coma.²¹ In a vegetative state a patient has sleep-wake cycles, her eyes will open, she can have some movement of her limbs, but she is nevertheless completely unaware of her surroundings. A person in a vegetative state has no thoughts or feelings, no pain or perception, and only reflexive movements and autonomic functions regulated by the still-functioning brain stem.²² A vegetative condition is diagnosed according to clinical observation.²³ If a person does enter a vegetative state, it can be diagnosed with a high degree of certainty as being permanent twelve months following a traumatic brain injury (such as from a fall) and after three months when the cause of the condition is non-traumatic (such as loss of oxygen to the brain from cardiac arrest).²⁴ Recovery after these time periods is extremely rare.²⁵

In the months following Terri Schiavo's cardiac arrest, Michael Schiavo and Terri's parents, Mary and Robert Schindler, were active partners in her care. According to a guardian ad litem's report filed in 2003, during this period of time "[t]here was no question but that complete trust, mutual caring, explicit love and a common goal of caring for and rehabilitating Theresa, were the shared intentions of Michael Schiavo [sic] and the Schindlers."²⁶ For a few weeks in 1990, Terri's family brought her home to care for her, but they found her needs overwhelming and she was returned to a skilled care facility.²⁷ She spent the remainder of her life in such facilities, hospitals, or hospice. Michael Schiavo took his wife to California for several

21. JENNETT, *supra* note 1, at 3–5 (setting forth definitional and clinical features of persistent vegetative state in adults); *see also* Am. Neurological Ass'n Comm. on Ethical Affairs, *Persistent Vegetative State: Report of the American Neurological Association Committee on Ethical Affairs*, 33 ANNALS NEUROLOGY 386, 386 (1993) (distinguishing between a coma and a vegetative state); Task Force Report, Part I, *supra* note 19, at 1499–1500 (setting forth the history and the current meaning of persistent vegetative state).

22. JENNETT, *supra* note 1, at 18–19 (discussing medical opinions regarding pain and awareness in the vegetative state patient). As Bryan Jennett, who, along with Fred Plum coined the term "vegetative" explains,

in the Oxford English dictionary. . . vegetative is used to describe "an organic body capable of growth and development but devoid of sensation and thought." It suggests even to the layman a limited and primitive responsiveness to external stimuli, whilst it reminds the doctor that there is relative preservation of autonomic regulation of the internal milieu of the body.

Id. at 4.

23. *See* Task Force Report, Part I, *supra* note 19, at 1500.

24. *Id.* at 1499.

25. JENNETT, *supra* note 1, at 57–65 (discussing data on recovery, late recovery and prediction of recovery).

26. WOLFSON REPORT, *supra* note 14, at 8.

27. *Id.*

months in 1990 so that she could receive aggressive rehabilitative therapy and even an experimental stimulator implant in her brain.²⁸ Periodic medical examinations revealed no improvement.

In 1992, Michael Schiavo sued the doctors who had been treating Terri Schiavo for infertility before her cardiac arrest. He alleged that the cardiac arrest was caused by a potassium imbalance linked to her dietary habits and bulimia.²⁹ A jury found that Terri Schiavo's doctors were negligent in failing to diagnose her condition; the case settled upon appeal and resulted in an award of \$300,000 for Michael Schiavo for loss of consortium and \$750,000 in economic damages for Terri Schiavo.³⁰ The money awarded to Terri Schiavo was placed in a trust for her continued care. An independent trustee was responsible for the trust funds, over which Michael Schiavo had no control.³¹ He would, however, inherit the money if she died. If he divorced her, then the Schindlers would inherit the money when she died.

It was around the time of the resolution of the lawsuit that Michael Schiavo and Mary and Robert Schindler fell out of friendship. The cause of this falling out is a matter of great dispute.³² Though not relevant to the legal and ethical questions explored in this article, the animosity between Michael Schiavo and the Schindlers became a very public matter and colored people's views about who was really looking

28. *Id.* at 9.

29. The guardian ad litem report notes:

The cause of the cardiac arrest was adduced to a dramatically reduced potassium level in Theresa's body. Sodium and potassium maintain a vital, chemical balance in the human body that helps define the electrolyte levels. The cause of the imbalance was not clearly identified, but may be linked, in theory, to her drinking 10-15 glasses of iced tea each day. While no formal proof emerged, the medical records note that the combination of aggressive weight loss, diet control and excessive hydration raised questions about Theresa suffering from Bulimia, an eating disorder, more common among women than men, in which purging through vomiting, laxatives and other methods of diet control becomes obsessive.

Id. at 8.

30. The Wolfson Report places the figure at \$750,000 for economic damages, while the original court order places the figure at \$700,000. *Id.* at 9; Schiavo Original 2000 Order, *supra* note 4, at 2.

31. WOLFSON REPORT, *supra* note 14, at 9.

32. Judge Greer writes in his original order about the cause of the falling out between Michael Schiavo and the Schindlers in February 1993:

While the testimony differs on what may or may not have been promised to whom and by whom, it is clear to this court that such severance [of the friendship] was predicated upon money and the fact that Mr. Schiavo was unwilling to equally divide his loss of consortium award with Mr. and Mrs. Schindler. The parties have literally not spoken since that date.

Schiavo Original 2000 Order, *supra* note 4, at 2.

out for Terri Schiavo's interests and who was motivated by their own interests. Specifically, in the years that would follow, the Schindlers repeatedly charged that Michael Schiavo was motivated by money to end Terri's life.³³ The trial court found no basis for these charges and would not remove Michael as Terri's guardian although repeatedly asked to do so on the grounds of conflict of interest.³⁴ The Schindlers also sought to remove Michael as guardian on the basis that he was not properly caring for Terri and, later, because he was living with another woman whom he called his "fiancée" and with whom he had fathered two children.³⁵ The court repeatedly concluded, however, that Michael Schiavo had been appropriately attentive to Terri's care.³⁶

In 1998, Michael Schiavo sought court approval for the removal of his wife's feeding tube.³⁷ Because she could not orally ingest sufficient quantities of food to sustain her body, Terri would die if doctors removed her feeding tube. The withdrawal of artificial nutrition and hydration from a person in a permanent vegetative state is permitted under Florida law by a health care proxy³⁸ as long as the decision is the

33. *Larry King Live: Interview with Mary, Robert Schindler* (CNN television broadcast Sept. 27, 2004) (transcript available at <http://edition.cnn.com/TRANSCRIPTS/0409/27/lkl.00.html>) (during which Robert Schindler suggests Michael Schiavo may have been motivated to end Terri Schiavo's life in order to secure for himself the funds remaining from malpractice award); see also Anita Kumar & J. Nealy-Brown, *Fund for Schiavo's Medical Care Dwindles*, ST. PETERSBURG TIMES ONLINE TAMPA BAY, June 3, 2001, http://www.sptimes.com/News/060301/TampaBay/Fund_for_Schiavo_s_me.shtml (detailing the potential conflicts of interest created by the malpractice award).

34. In fact, in its original order, the trial court explained that both Michael Schiavo and the Schindlers could be understood as having a conflict of interest in the decision-making process of Terri Schiavo. Schiavo Original 2000 Order, *supra* note 4, at 2-3. If, through legal maneuvering, the Schindlers were able to keep their daughter alive long enough that Michael Schiavo would seek a divorce, then they would stand to inherit from her estate. See also Report of Guardian Ad Litem, Richard L. Pearse, Jr. at 7-9, *In re Schiavo*, No. 90-290BGD-003 (Fl. Cir. Ct. Dec. 29, 1998), available at <http://www.miami.edu/ethics/schiavo/122998%20Schiavo%20Richard%20Pearse%20GAL%20report.pdf> (describing an early failed attempt by the Schindlers to remove Michael Schiavo as guardian and crediting their concern about his actual or at least apparent conflict of interest).

35. See Jamie Thompson, *She's the Other Woman in Michael Schiavo's Heart*, ST. PETERSBURG TIMES ONLINE TAMPA BAY, Mar. 26, 2005, http://www.sptimes.com/2005/03/26/news_pf/Tampabay/She_s_the_other_woman.shtml (discussing Michael Schiavo's relationship with his live-in girlfriend).

36. See, e.g., Schiavo Original 2000 Order, *supra* note 4, at 3-4 (noting that Michael Schiavo had taken his wife to California for experimental treatment, had been aggressive with nursing home personnel, and was otherwise very attentive to her care). Jay Wolfson, in his 2003 guardian ad litem report notes "[Michael's] demanding concern for [Terri's] well being and meticulous care by the nursing home earned him the characterization by the administrator as 'a nursing home administrator's nightmare'. [sic] It is notable that through more than thirteen years after Theresa's collapse, she has never had a bedsore." WOLFSON REPORT, *supra* note 14, at 10.

37. Schiavo Original 2000 Order, *supra* note 4, at 1, 4.

38. Under Florida law, a health care proxy is a person designated by statute to make decisions

one that the patient would make or the withdrawal of treatment is in the patient's best interests.³⁹ By Florida statute, Michael Schiavo was his wife's proxy because she had not designated anyone prior to her incapacity. The statutory law of Florida, like that of other states, establishes a hierarchy of family members to step in as proxy with the power to make certain medical treatment decisions for patients.⁴⁰ In certain circumstances, proxies may decide to withdraw life support.⁴¹

The withdrawal of feeding tubes from patients in a permanent vegetative state takes place on a regular basis in hospitals and nursing homes across the country without any court involvement.⁴² State law may even specify, as Florida's does, that court approval is not necessary

for an incapacitated person who has not executed an advance directive appointing someone to serve as surrogate. As Kathy Cerminara explains, "This terminology contrasts with that used in other states, in which persons making medical decisions for incapacitated persons without patient appointment to such a position (. . . those who derive their authority from operation of law) are called surrogates." Kathy L. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 35 STETSON L. REV. (forthcoming 2006) (manuscript at n.3, on file with author). In this article, the terms are generally used interchangeably. When it is relevant whether the agent was appointed by the patient or designated according to state, attention is drawn to that distinction.

39. FLA. STAT. § 765.401(2), (3) (2004).

40. FLA. STAT. § 765.401(1) (2004). The following individuals may act as proxy in the following order of priority: (a) the judicially appointed guardian of the patient; (b) the patient's spouse; (c) an adult child of the patient or, if the patient has more than one adult child, a majority of adult children; (d) a parent of the patient; (e) the adult sibling of the patient or, if the patient has more than one sibling, a majority of the adult siblings; (f) an adult relative who has exhibited special care and concern for the patient; (g) a close friend of the patient; (h) in some circumstances, a clinical social worker. *Id.*

41. *Id.* As explained in more detail *infra*, the Florida statutes explicitly permit a proxy to withdraw life support when the patient is in one of three conditions—a persistent vegetative state, an end-stage condition, or is terminally ill, FLA. STAT. § 765.305(2)(b) (2004)—and there is clear and convincing evidence that the patient would wish to be removed from life support in that condition or the removal of life support would be in the patient's best interests. See *infra* notes 90–94 (discussing Florida statutes related to surrogate or proxy decision-making).

42. This seems to be a matter of common knowledge, rather than an issue that has been statistically verified. See, e.g., Lee Benson, *Schiavo Story Blown Far Our of Proportion*, DESERET MORNING NEWS, Apr. 4, 2005, at B01 ("Every day, ventilators are shut off and feeding tubes are removed in hospitals and hospices. . . ."); David C. Leven, *Oregon Assisted-Dying Law Should Stand*, J. NEWS, Oct. 3, 2005, at 4B ("Every day, throughout the U.S., people decide, as they legally can, to have feeding tubes removed or not inserted in the first place. . . ."); see also David Orentlicher & Christopher M. Callahan, *Feeding Tubes, Slippery Slopes, and Physician-Assisted Suicide*, 25 J. LEGAL MED. 389, 402 (2004) ("The literature reports data on the number of feeding tubes inserted, but we do not have data on the number of patients for whom feeding was discontinued or never started."). It is, however, quite well settled that judicial review of such decisions is not normally required. MEISEL & CERMINARA, *supra* note 3, § 3.19 ("A presumption against judicial review of decisions made by properly designated surrogates to forego life-sustaining treatment began to emerge beginning with the earliest end-of-life cases. . . . This presumption is now well solidified.").

prior to withdrawal of medical treatment.⁴³ Nevertheless, Michael Schiavo was aware that the Schindlers disagreed with his decision to remove Terri's feeding tube, and he asked the local probate court to determine if the feeding tube should be removed. If he had not sought court review, the Schindlers could have done so without Michael's consent under the Florida procedures for end-of-life decision making.⁴⁴

The case was assigned to Circuit Judge George Greer, who would see the case go through numerous permutations over seven years. After the initial hearing, in which witnesses gave testimony, Judge Greer determined that Terri Schiavo was "beyond all doubt . . . in a persistent vegetative state" and that the medical evidence "conclusively establishes that she has no hope of ever regaining consciousness"⁴⁵ A CAT scan introduced into evidence revealed that "to a large extent her brain ha[d] been replaced by spinal fluid"⁴⁶ The trial court's other central finding was that there existed clear and convincing evidence that removal of the feeding tube was the decision Terri Schiavo herself would make if she were competent.⁴⁷ This evidence consisted of statements reportedly made by Terri Schiavo to her husband, his brother, and his sister-in-law. The statements concerned instances in which Terri would not want to continue living, and Terri made those statements in response to the hospitalization of her grandmother, the funeral of another relative, a television movie, and a report or show on television regarding people on life support.⁴⁸ The trial court ordered, on the basis of this evidence, that the feeding tube should be removed.

Over the next year, the Schindlers unsuccessfully appealed this original order,⁴⁹ and Terri Schiavo's feeding tube was clamped in April

43. *In re Browning*, 568 So. 2d 4, 15 (Fla. 1990) (stating that when a patient has expressed his or her desires, a surrogate need not obtain prior judicial approval to carry out those desires, including terminating life-sustaining measures).

44. FLA. STAT. § 765.105 (2004) (permitting the patient's family, health care facility, attending physician, or other interested persons to seek expedited judicial intervention for review of a surrogate or proxy's decision).

45. Schiavo Original 2000 Order, *supra* note 4, at 6.

46. *Id.*

47. *Id.* at 6, 8–10. The Florida statutes provide that a proxy's decision to withhold or withdraw life-prolonging procedures "must be supported by clear and convincing evidence that the decision would have been the one the patient would have chosen had the patient been competent or, if there is no indication of what the patient would have chosen, that the decision is in the patient's best interest." FLA. STAT. § 765.401(3) (2004).

48. Schiavo Original 2000 Order, *supra* note 4, at 9.

49. *In re Schiavo*, 780 So. 2d 176, 180 (*Schiavo I*) (Fla. Dist. Ct. App.) (affirming the Schiavo Original 2000 Order), *review denied sub nom.* Schindler v. Schiavo *ex. rel.* Schiavo, 789 So. 2d 348 (Fla. 2001).

2001, meaning that she stopped receiving nutrition and hydration through the tube.⁵⁰ The Schindlers then filed a new legal action in a different division of the circuit courts of Florida, requesting that the removal of life support be enjoined.⁵¹ A different judge, unfamiliar with the case, reviewed the evidence under emergency review and ordered feeding to be resumed.⁵² Through a series of motions and additional reviews at the appellate level, this request by the Schindlers resulted in the unclamping of their daughter's feeding tube and a new evidentiary hearing by Judge Greer as to her condition.⁵³

The purpose of the new hearing was to allow the Schindlers to establish that new medical treatment offered significant promise of improving Terri's condition such that Terri herself would have changed her mind about discontinuing feeding, had she been capable of making such a decision.⁵⁴ Five doctors submitted expert testimony on Terri Schiavo's condition—two chosen by Michael Schiavo, two by the Schindlers, and one by the court.⁵⁵ Judge Greer also viewed four-and-a-half hours of videotape footage of Terri Schiavo, select portions of which would later repeatedly air on national television.⁵⁶ Following the hearing, Judge Greer ruled that "the credible evidence overwhelmingly supports the view that Terry [sic] Schiavo remains in a persistent vegetative state."⁵⁷ In addition, the Schindlers offered no testimony that revealed treatment options that would significantly improve Terri's quality of life.⁵⁸ The court consequently entered a new order to withdraw Terri's feeding tube.⁵⁹

When court challenges in October 2003 to this second order were unsuccessful,⁶⁰ the Schindlers and their many supporters among right-to-life and disability advocacy groups sought the intervention of Florida

50. *In re Schiavo*, 792 So. 2d 551, 555 (*Schiavo II*) (Fla. Dist. Ct. App. 2001).

51. The Schindlers' tactics are discussed in some detail in the opinion of the Second District Court of Appeal in *Schiavo II*. *Id.*

52. *Id.* at 555–57.

53. *In re Schiavo*, 800 So. 2d 640, 647–48 (*Schiavo III*) (Fla. Dist. Ct. App. 2001) (ordering new hearing on medical evidence).

54. *Id.* at 645–47.

55. *In re Schiavo*, No. 90-2908-GB-003, 2002 WL 31817960, at *1 (Fla. Cir. Ct. Nov. 22, 2002) (circuit court decision denying the Schindlers' motion to reverse the original 2000 court order and continue life-sustaining activities for Terri Schiavo).

56. *Id.* at *2–3.

57. *Id.* at *3.

58. *Id.* at *5.

59. *Id.*

60. *In re Schiavo*, 851 So. 2d 182 (*Schiavo IV*) (Fla. Dist. Ct. App.), *review denied sub. nom.* *Schindler v. Schiavo*, 855 So. 2d 621 (Fla. 2003).

Governor Jeb Bush. Besieged by e-mails, letters, and telephone calls, the Florida legislature rushed through special legislation specifically dealing with Terri Schiavo's situation. This legislation allowed the governor to issue a "stay" of the order allowing the feeding tube to be withdrawn and permitted him to order the feeding tube's reinsertion, which he did.⁶¹ The legislation, known as "Terri's Law," also provided for appointment of a guardian ad litem to make recommendations to Governor Bush and the court.

The actions of the Florida legislature and Governor Bush were unprecedented.⁶² Supporters of the governor's intervention likened it to a "stay of execution."⁶³ From their perspective, Terri Schiavo was a

61. The Florida legislation provided:

Section 1. (1) The Governor shall have the authority to issue a one-time stay to prevent the withholding of nutrition and hydration from a patient if, as of October 15, 2003:

- (a) That patient has no written advance directive;
- (b) The court has found that patient to be in a persistent vegetative state;
- (c) That patient has had nutrition and hydration withheld; and
- (d) A member of that patient's family has challenged the withholding of nutrition and hydration.

(2) The Governor's authority to issue the stay expires 15 days after the effective date of this act, and the expiration of that authority does not impact the validity or the effect of any stay issued pursuant to this act. The Governor may lift the stay authorized under this act at any time. A person may not be held civilly liable and is not subject to regulatory or disciplinary sanctions for taking any action to comply with a stay issued by the Governor pursuant to this act.

(3) Upon the issuance of a stay, the chief judge of the circuit court shall appoint a guardian ad litem for the patient to make recommendations to the Governor and the court.

Section 2. This act shall take effect upon becoming a law.

H.B. 35-E, 2003 Leg., Spec. Sess. (Fla. 2003), available at http://www.miami.edu/ethics/schiavo/102003_HB35-E.pdf. "Terri's Law" was invalidated by *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004).

62. Although on previous occasions state officials have intervened in end-of-life disputes, they have not had specific legislative backing such as that provided by Terri's Law. The closest parallel appears to be the case of Hugh Finn, a Virginia man living in a permanent vegetative state whose wife sought removal of artificial nutrition and hydration. The Governor of Virginia vigorously opposed the trial court's order approving removal of artificial nutrition and hydration and filed a separate lawsuit to that end, which ultimately failed. See Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo Controversy*, 59 U. MIAMI L. REV. 107, 121-22 (2004), for a discussion of this intervention.

63. See, e.g., Adam Liptak, *In Florida Right-to-Die Case, Legislation that Puts the Constitution at Issue*, N.Y. TIMES, Oct. 23, 2003, at A20 ("It's beautifully badly drafted," said Patrick O. Gudridge, a law professor at the University of Miami. . . . "They wanted to use the word stay," Professor Gudridge said of the Legislature, "because the analogy is to a stay of execution."); David Sommer, *Advocacy Group Supports Schindlers in Court Fight*, TAMPA TRIB., Oct. 31, 2003, Metro, at 3 (quoting chief counsel for the American Center for Law and Justice: "We think the Legislature and the governor have a role here. . . . The governor has the right to stay executions ordered by the courts, and has a similar right to intervene when family members disagree about life-ending decisions for loved ones who cannot speak for themselves.");

severely disabled individual about to be cruelly starved to death, and they believed she should be entitled to at least the protection afforded those who had committed capital crimes.⁶⁴ Florida legislators appeared largely out of their depth, both in their knowledge of existing Florida law and constitutional precedent and in their understanding of the facts surrounding the case.⁶⁵ But there was no time to lose if they were to “save” Terri Schiavo. Debate on the floor of the legislature was intense, including both political grandstanding and emotional, sometimes even tearful, good will.⁶⁶

Opponents of the legislation were aghast at the intrusion of the legislature and executive into an individual’s medical decisions.⁶⁷ Critics charged that the legislature and governor had unconstitutionally invaded the province of the judiciary and violated constitutional due process guarantees by singling out a particular and already adjudicated case for reversal by special legislation.⁶⁸ There were also strong criticisms that Governor Bush had essentially replaced Michael Schiavo as Terri Schiavo’s health care proxy and thus encroached on her constitutional rights.⁶⁹

In 2004, the Florida Supreme Court declared “Terri’s Law” unconstitutional as a violation of the separation of powers doctrine.⁷⁰ Terri Schiavo’s feeding tube was once again set for removal, prompting yet another legislative consideration of her situation. In early 2005, as

Cal Thomas, Editorial, *Jeb Bush’s Controversial Stay of Execution*, AUGUSTA CHRON., Oct. 27, 2003, at A04 (likening the governor’s power to intervene in capital cases to his power to intervene in Schiavo controversy).

64. See Sommer, *supra* note 63.

65. See Liptak, *supra* note 63.

66. Abby Goodnough, *Governor of Florida Orders Woman Fed in Right-to-Die Case*, N.Y. TIMES, Oct. 22, 2003, at A1 (“Many lawmakers drew on their own religious beliefs and experiences with death, sometimes choking up as they described the drawn-out illness of a parent or spouse.”); William March, *Schiavo Law Fuels Debate of Politics*, TAMPA TRIB., Oct. 23, 2003, Nation/World, at 1 (“‘Nothing more than political grandstanding . . . a cheap and easy way to look good to the public,’ declared businessman J. Jay Schwartz of Oldsmar, one of more than 500 people who sent e-mail to TBO.com late Tuesday and Wednesday responding to the case.”).

67. See Liptak, *supra* note 63 (discussing reactions to the proposed legislation).

68. *Id.*

69. Lucy Morgan, *Keeping Politicians out of Your Final Days*, ST. PETERSBURG TIMES, Nov. 1, 2003, at 1B (stating that a Floridian’s right to refuse medical treatment is grounded in Floridian’s constitutional right to privacy); Lois Shepherd, Op-Ed., *Gov. Bush: Health Care Surrogate?*, TALLAHASSEE DEMOCRAT, Oct. 26, 2003, at 5E.

70. *Bush v. Schiavo*, 885 So. 2d 321, 336–37 (Fla. 2004). Terri Schiavo’s liberty and privacy interests were also arguably violated by the law, a point made by the lower court but bypassed by the Florida Supreme Court. *Schiavo v. Bush*, No. 03-008212-CI-20, 2004 WL 980028, at *3–4 (Fla. Cir. Ct. May 5, 2004). For a discussion of the separation of powers issues implicated by Terri’s Law, see Noah, *supra* note 62, at 121–23.

the third removal of Terri's feeding tube was drawing near, the Florida legislature considered a bill that would ostensibly avoid the separation of powers infirmities of Terri's Law, but nevertheless would apply to Terri Schiavo's situation.⁷¹ This time it was not legislation specific to her, but covered all people in a permanent vegetative state and required more specific evidence of a patient's desire to have nutrition and hydration removed in these circumstances than required under the existing law. The Florida House passed one version of a bill;⁷² the Florida Senate considered another, but rejected it by a few votes.⁷³ Terri Schiavo's feeding tube was removed for the third time on March 18, 2005.⁷⁴ What amounted to a national death watch played continually on televised media.

Even more extraordinary than the actions of the Florida legislature and governor in 2003, in 2005 Terri Schiavo's case became the subject of involvement by the U.S. Congress. First, on the date of the feeding tube's removal in 2005, subpoenas were issued for Terri Schiavo, her husband, and others involved in the case to appear before a congressional committee.⁷⁵ Terri Schiavo was subpoenaed under a theory that failing to provide her with artificial nutrition and hydration would constitute an illegal obstruction of the subpoena.⁷⁶ Judge Greer, however, decided that the congressional subpoena would not affect the order requiring the removal of the feeding tube.⁷⁷ Then, Congress passed a law granting federal court jurisdiction over this particular case, by name, stating that review should be *de novo*.⁷⁸ The federal court hearing the matter decided that a preliminary injunction ordering reinsertion of the feeding tube would not be granted, however, because the parents of Terri Schiavo had not shown a substantial likelihood of success on the merits of their claim that there had been inadequate

71. H.R. 701, 2005 Leg., Reg. Sess. (Fla. 2005), S. 804, 2005 Leg., Reg. Sess. (Fla. 2005).

72. H.R. 701, 2005 Leg., Reg. Sess. (Fla. 2005).

73. S. 0804, 2005 Leg., Reg. Sess. (Fla. 2005); Stephen Nolgren, "I'm Here Because I Care," *Jackson Tells Crowd*, ST. PETERSBURG TIMES, Mar. 30, 2005, at 11A (explaining how the measure failed 21-18).

74. Maya Bell & Etan Horowitz, *Schiavo's Feeding is Stopped Despite Last-Ditch Congressional Action*, BALT. SUN, Mar. 19, 2005, at 1A.

75. Adam Liptak, *With Schiavo Subpoenas, Lawmakers Leap into Contested Territory*, N.Y. TIMES, Mar. 19, 2005, at A12.

76. William R. Levesque et al., *Tube is Removed After Chaotic Day*, ST. PETERSBURG TIMES, Mar. 19, 2005, at 1A.

77. *Id.*; Phil Long et al., *Judge Rejects Congress' Subpoena*, MIAMI HERALD, Mar. 19, 2005, at 1A.

78. An Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005).

process in the state courts.⁷⁹ In making this decision, the federal court considered the extent of process that had taken place in the state courts over seven years, rather than ignoring the fact that the case had been through the state courts, as the drafters of the legislation appeared to have assumed, or at least hoped, the court would do.

Florida Governor Jeb Bush then made one last-ditch effort to restore Terri's feeding tube through the powers of the Florida Department of Children and Families (DCF) and the Florida Department of Law Enforcement. DCF previously sought intervention in the case, but did not succeed.⁸⁰ In fact, Judge Greer entered an order forbidding DCF from "taking possession" of Terri, but because that order was automatically stayed upon the filing of an appeal, DCF apparently intended to take Terri Schiavo from the hospice with the aid of the Florida state police.⁸¹ When made aware of the effect of the automatic stay, Judge Greer canceled it, but not before a squad of state police and DCF officials were en route to the hospice where Terri Schiavo was cared for, with apparent intent to remove her to a hospital for reinsertion of the feeding tube. Before they arrived, however, local police told the state agents they would not allow Terri to be removed without a court order; state agents then backed down. The *Miami Herald* quoted one official's description of the day's events: "There were two sets of law enforcement officers facing off, waiting for the other to blink . . ." ⁸² State officials later denied any suggestion that a "showdown" had occurred.⁸³

Terri Schiavo died on March 31, 2005, as the public obtained hourly

79. Schiavo *ex rel.* Schindler v. Schiavo, 358 F. Supp. 2d 1161, 1167 (M.D. Fla. 2005).

80. Petition/Motion for Intervention, Stay of Order of the Probate Court, Appointment of Legal Counsel for Theresa Marie Schiavo and Sealing of the Proceedings, Schiavo *ex rel.* Schindler v. Schiavo, 358 F. Supp. 2d 1161, 1161 (M.D. Fla. 2005) (No. 2908GD-003), available at <http://abstractappeal.com/schiavo/DCFpetition.pdf> (filing by representative of Florida Department of Children and Families on February 23, 2005); Schiavo *ex rel.* Schindler v. Schiavo, No. 2908GD-003 (M.D. Fla. Mar. 10, 2005), available at <http://abstractappeal.com/schiavo/trialctorder031005.pdf> (denying the February petition and ruling that intervention by DCF was not appropriate).

81. Carol Marbin Miller, *Terri Schiavo Case: Plan to Seize Schiavo Fizzles*, MIAMI HERALD, Mar. 26, 2005, at 1A. DCF's second petition for intervention, filed March 23, 2005, is available at <http://abstractappeal.com/schiavo/DCFpetition2.pdf> (last visited Nov. 28, 2005). The petition was denied. The Terri Schiavo Information Page, <http://abstractappeal.com/schiavo/infopage.html> (last visited Jan. 7, 2006) (discussing the Schiavo case timeline); see also Carl Jones, *Appellate Review*, MIAMI DAILY BUS. REV., Sept. 26, 2005, at 18 (reporting Florida appellate court's issuance of explanation for its decision to uphold Judge Greer's Mar. 23, 2005 emergency order to prevent DCF from removing Terri Schiavo from the hospice).

82. Miller, *supra* note 81.

83. *Id.*

updates by radio, the Internet, and television. The last few days of Terri's life were as bitterly contentious as the previous decade's fight over the decision to discontinue life support. As reported by the media, Michael Schiavo and the Schindler family fought over who would spend time with Terri, over the performance of religious last rites, over whether she would be cremated or buried and over where her remains would be placed.⁸⁴

III. QUESTIONS RAISED BY THE SCHIAVO CONTROVERSY

The Schiavo controversy prompts many questions about end-of-life decision-making law and its future. This Part offers ways of thinking about three of them and poses three questions: What is the role of surrogate decision-making?⁸⁵ Under what conditions should the withdrawal of life-sustaining treatment be permitted by surrogate decision-makers?⁸⁶ How does the removal of artificial nutrition and hydration relate to other forms of treatment?⁸⁷

A. *How much deference should be given to surrogate decision-makers? How should the interests of family members, or others close to the patient, be weighed against respecting the preferences or best interests of the patient?*⁸⁸

Throughout the unfolding story of Terri Schiavo and the fight between her husband and her parents, the following remark could be repeatedly heard from many of those who supported the decision to withdraw Terri Schiavo's feeding tube: "But it's the husband's decision, right?" Not exactly. Constitutional law, common law, and statutory law, as they have developed in this area, all agree that there are two main considerations at work in determining treatment decisions for the incompetent patient—the patient's self-determination and the patient's interests.⁸⁹ As between the two, primary emphasis is placed upon respecting the patient's preferences if they can be determined, rather

84. Ellen Gamerman, *Schiavo's Family Urges Jeb Bush to Act as Legal Appeals Fail; Schindlers, Husband Clash over Wide Range of Issues*, BALT. SUN, Mar. 27, 2005, at 10A.

85. See *infra* Part III.A (discussing the appropriate level of deference to surrogates).

86. See *infra* Part III.B (discussing the varying physical conditions and whether surrogates should be able to withdraw life-sustaining treatment during each condition).

87. See *infra* Part III.C (considering whether nutrition and hydration should be treated as basic or required medical needs).

88. These questions are explored in more depth in Lois Shepherd, *Shattering the Neutral Surrogate Myth in End-of-Life Decisionmaking: Terri Schiavo and Her Family*, 35 CUMBERLAND L. REV. 575, 588, 595 (2005).

89. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484, 493 (Cal. Ct. App. 1983) (giving the typical formulation of this standard); MEISEL & CERMINARA, *supra* note 3, § 4.01[A] & [B].

than conducting an objective weighing of her interests in accepting or refusing treatment.⁹⁰ Thus, for surrogate decision-making, the legal standard the courts have adopted is that the surrogate (or “proxy,” as it is called in Florida) expresses for the patient what the patient would want done. It is the *patient’s* decision, not the husband’s or the parents’, or, as it used to be, the physician’s.⁹¹

Because the law seeks to determine and respect what the patient would want in regards to continuing or discontinuing treatment, the issue of who actually serves as health care proxy should not theoretically be of great significance.⁹² Yet, the Schiavo controversy revealed very clearly that it *does* matter who is named proxy. If either of the Schindlers had been named proxy prior to the original 2000 court order, they would have requested the continuation of their daughter’s

90. *Barber*, 195 Cal. Rptr. at 493; MEISEL & CERMINARA, *supra* note 3, § 4.01[A] & [B]. Florida has adopted this same standard in caselaw and by statute:

We emphasize and caution that when the patient has left instructions regarding life-sustaining treatment, the surrogate must make the medical choice that the patient, if competent, would have made, and not one that the surrogate might make for himself or herself, or that the surrogate might think is in the patient’s best interests.

In re Browning, 568 So. 2d 4, 13 (Fla. 1990).

[A] proxy’s decision to withhold or withdraw life-prolonging procedures must be supported by clear and convincing evidence that the decision would have been the one the patient would have chosen had the patient been competent or, if there is no indication of what the patient would have chosen, that the decision is in the patient’s best interest.

Fla. Stat. § 765.401(3) (2004).

91. The Florida Supreme Court emphasized this point in *Browning*: “One does not exercise another’s right of self-determination or fulfill that person’s right of privacy by making a decision which the state, the family, or public opinion would prefer. The surrogate decisionmaker must be confident that he or she can and is voicing the *patient’s* decision.” *Browning*, 568 So. 2d at 13.

On the issue of past deference to physician decisions in these and other matters relating to medical treatment, see generally DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING* 1–2 (1991). Rothman writes:

Well into the post-World War II period, decisions at the bedside were the almost exclusive concern of the individual physician, even when they raised fundamental ethical and social issues. It was mainly doctors who wrote and read about the morality of withholding a course of antibiotics and letting pneumonia serve as the old man’s best friend, of considering a newborn with grave birth defects a ‘stillbirth’ and sparing the parents the agony of choice and the burden of care. . . . Moreover, it was usually the individual physician who decided these matters at the bedside or in the privacy of the hospital room, without formal discussions with patients, their families, or even with colleagues, and certainly without drawing the attention of journalists, judges, or professional philosophers.

Id.

92. See *supra* note 40, for the list of individuals who can serve as proxy under Florida law when the patient has not herself, through an advance directive, named someone to serve as her surrogate.

feeding tube, and almost certainly that request would have been granted. They would not have been required to get court approval for continued feeding, and they would easily have been able to find a physician and long-term care facility to concede to their request.⁹³ Indeed, the request to continue the feeding tube would have been assumed.⁹⁴ The feeding tube, then, would have remained in place until Terri Schiavo died of other causes, which might not have occurred for another twenty or thirty years.⁹⁵ As explained below, this result would likely have occurred even if Terri herself wanted the feeding tube removed, as a court in this case had found.⁹⁶ Remarkably, although our legal standard does not *appear* to allow a degree of discretion granting surrogates the authority to decide whatever *they* would want for an incompetent patient, it unfortunately does so.

How is this the case and should we be bothered by it? The combination of two factors produces such results: first, the lack of judicial review for treatment decisions generally and, more particularly, the lack of judicial review of decisions *to continue treatment*; and second, the presumption in favor of life-sustaining treatments, including artificial nutrition and hydration.⁹⁷ Together, these two factors mean that a decision to continue treatment is not often subjected to any sort of review, whereby proxies are put to the task of producing evidence of the patient's preferences. It is only when a decision is made to discontinue life-sustaining treatment that the proxy's decision must be based on clear and convincing evidence regarding patient preferences.⁹⁸ Thus, to

93. See COLBY, *supra* note 2, at 361–62 (describing the difficulty the Cruzan family faced in finding health care providers to concede to their request to have Nancy Beth Cruzan's feeding tube removed, even when the court approved its removal); see also Orentlicher & Callahan, *supra* note 42, at 397 (suggesting generally that feeding tubes can be overused).

94. This is so because the proxy's removal of the feeding tube must be supported by clear and convincing evidence that removal is appropriate, *Browning*, 568 So. 2d at 15; Fla. Stat. § 765.401(3) (2004), whereas a proxy's decision to continue feeding would not be subject to the same scrutiny. See *infra* text accompanying notes 97–98 (discussing the lack of judicial review over feeding tube continuation and the presumption in favor of continued feeding).

95. See JENNETT, *supra* note 1, at 65–69 (describing the life expectancy of people in a permanent vegetative state).

96. See *supra* notes 45–46 (describing the evidence cited by the court that showed, to a clear and convincing standard that Terri would have wanted the feeding tube removed).

97. The presumption in favor of life is manifested in the requirement that it is only when a decision is made to discontinue life-sustaining treatment that the proxy's decision must be based on clear and convincing evidence regarding the patient's preferences or her best interests. See *Browning*, 543 So. 2d at 273, for a discussion of how this standard of evidence for treatment refusals for incompetent patients works to "err on the side of life." See also *Schiavo I*, 780 So. 2d 176, 179 (Fla. Dist. Ct. App. 2001) (reconfirming that a court's default position must favor life).

98. The clear and convincing standard is an intermediate standard between a preponderance of the evidence (the typical civil standard of proof) and beyond a reasonable doubt (the typical

continue treatment the Schindlers would not need clear and convincing evidence that their daughter would have wished treatment continued and, in fact, could probably have continued treatment even when others might have produced strong evidence that she would have wanted it discontinued.

If Terri Schiavo had executed a living will clearly expressing a desire not to continue feeding in a permanent vegetative state, that might have sufficed to overcome the deference to the proxy's decision to continue treatment, but mere oral evidence would unlikely have been enough.⁹⁹ Even a living will can be challenged as insufficiently directive, or as having been coerced or executed without proper knowledge of the circumstances, or as being outdated and no longer expressing the wishes of the patient.

In our hypothetical, where one of Terri Schiavo's parents acted as proxy without a living will, the proxy's decision to continue perpetual feeding would almost certainly have prevailed, and there would likely have been no challenge to that decision or any controversy surrounding it. If she had been in a condition in which she experienced pain or suffered in any way from continued feeding, however, then the situation might have been viewed differently, and health care providers or family members might have been able to challenge successfully a decision to continue feeding. But a patient in a permanent vegetative state does not experience pain or suffering, and courts have not been willing to give much weight to the burden of indignity that some believe is associated with living in a state of permanent unconsciousness (which also, of course, cannot be experienced by such a patient).¹⁰⁰ Thus, because

criminal standard of proof). The majority opinion in *Cruzan* noted that clear and convincing evidence was that which

produces in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established, evidence so clear, direct and weighty and convincing as to enable [the factfinder] to come to a clear conviction, without hesitancy, of the truth of the precise facts in issue.

Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 285 (1990) (citing *In re Jobes*, 108 N.J. 394 (1987)).

99. In Florida, a written living will establishes a rebuttable presumption that constitutes clear and convincing evidence of the patient's wishes. *Browning*, 568 So. 2d at 16.

100. See, e.g., *DeGrella v. Elston*, 858 S.W.2d 698, 705 (Ky. 1993) (stating that best interests analysis would not be adopted), *limited by* *Woods v. Commonwealth*, 142 S.W.3d 24 (Ky. 2004); *Mack v. Mack*, 618 A.2d 744, 759 (Md. 1993) (refusing to allow best interest analysis to be applied to patient in a permanent vegetative state without legislative guidelines); *In re Peter*, 529 A.2d 419, 425 (N.J. 1987) (“[A] benefits-burden analysis . . . is essentially impossible with patients in a persistent vegetative state.”); see also 73 Op. Md. Att’y Gen. 162, 189–90 (1988) (“The balancing of costs and benefits to the patient that a surrogate must undertake for a terminally ill patient cannot be done in the same way for a patient who is permanently unconscious.”) (emphasis added).

Terri Schiavo experienced no burden by continued feeding, it would have been difficult for anyone to challenge successfully the Schindlers' treatment decision in court in this hypothetical situation.

This is not to say that the same result would have been obtained if the Schindlers had been successful in replacing Michael Schiavo as proxy *after* the 2000 court order that authorized the removal of the feeding tube. (Recall that in our hypothetical scenario, one of the Schindlers becomes proxy before that time.) Because the court in 2000 determined that Terri would have wished to discontinue tube feeding, the proxy was at that point bound to follow the court's determination of the patient's wishes. The Schindlers' reluctance to do so would have made them inappropriate proxies for their daughter. What the *Schiavo* case reveals is how much freedom proxies have to make these decisions when they are not reviewed by courts. And such cases are less likely to come before a court when the decision is made in favor of non-burdensome treatment.

According to Florida statutes, in the early years of Terri Schiavo's vegetative state, either Michael Schiavo or one of the Schindlers could have served as her proxy, although Michael Schiavo had statutory priority as her spouse.¹⁰¹ The fact that family members with such diverse views of the appropriateness of continued treatment might qualify to serve as proxies and the fact that the view of only one (the one with statutory priority) generally prevails, is obviously troubling. How can we say that our system of family surrogate¹⁰² decision making respects the patient's wishes or interests if such opposing results can occur; here, the parents favored continued treatment (life) and the spouse favored its discontinuation (death)?

Though we should find this result troubling, that does not mean that we should abandon the system of family surrogates or require judicial review of every significant medical treatment decision for incompetent patients. Family decision making is valuable for reasons other than the family members' supposed competency to speak for the patient.¹⁰³ We value family surrogate decision making in part because many people

101. See priority listing, *supra* note 40 (listing the priority of proxies under Florida law).

102. When speaking of the "family surrogate" I mean to use the word "family" in a very broad sense. The Florida statutes, for example, include "close friend" in the list of those who might become a patient's proxy. See *supra* note 40, for a list of the persons who may serve as proxy in Florida.

103. See PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & MED. & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: ETHICAL, MED., AND LEGAL ISSUES IN TREATMENT DECISIONS 126-28 (1983). For a fuller discussion of this point, see Shepherd, *supra* note 88.

want family members to speak for them, or even to do more—to make decisions for them when they lose competency.¹⁰⁴ Family members also have a great amount at stake in these decisions involving their loved ones—much of which we should respect and value.¹⁰⁵

The deference accorded to family surrogates to continue treatment may be justified in the case of the terminally ill patient. In such cases, if the treatment is not burdensome in a way that is experienced by the patient, then the law may be striking the right balance by deferring to family members who are making choices in favor of life that they believe are appropriate, even if it means at times that the patient's preferences to die sooner or avoid certain treatments are not always honored. To always, or even routinely, insist upon a judicial discernment of the preferences of the patient would cause an intrusive disruption by the state into matters generally considered private. Often the patient's preferences will not be clear in any event, sometimes even when a written directive exists.¹⁰⁶ Even assuming that judicial involvement means that patient preferences are honored more often, the extra burdens imposed upon the family by state involvement may well not be justified by the satisfaction of patient preferences to avoid only a few days or weeks of unwanted life.

This sort of accommodation of a family surrogate's decision to continue treatment, however, is more problematic when the patient is *not* terminally ill but is instead in a permanent vegetative state. For the person in a permanent vegetative state, the ease with which a surrogate can continue tube feeding even if that is not what the patient would want more clearly fails to respect that person's autonomy. Instead of a few unwanted days of life in a diminished condition, the result could be a few unwanted decades of life, as we can imagine would have happened in the *Schiavo* case if the Schindlers had been named proxy.

What this suggests is that the law should provide different rules for effectuating patient choice to refuse treatment when the patient has entered a permanent vegetative state. The law should provide judicial or quasi-judicial review of decisions to feed patients indefinitely in a

104. *Id.* Most Americans believe that family members should make end-of-life treatment decisions for their close relatives. See Stephen C. Hines, Ph.D. et al., *Dialysis Patients' Preferences for Family-Based Advance Care Planning*, 130 ANNALS OF INTERNAL MED. 825, 825–28 (1999); see also *In re Jobes*, 529 A.2d 434, 446, n.11 (N.J. 1987) (reporting on surveys); D.M. High, *All in the Family: Extended Autonomy and Expectations in Surrogate Health Care Decision-Making*, THE GERONTOLOGIST, 28, 46–51 (Supp. 1988).

105. Shepherd, *supra* note 88, at 585.

106. See generally Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CENTER REP., 30, 30–42 (2004) (describing the inadequacies of living wills).

permanent vegetative state because of the profound effect that such decisions have.¹⁰⁷ The law should also consider removing the presumption in favor of life in such instances¹⁰⁸ because an error by the surrogate in reflecting patient preferences can, as Justice Brennan stated years ago in *Cruzan*, “rob a patient of the very qualities protected by the right to avoid unwanted medical treatment.”¹⁰⁹ Just as a decision to withdraw life support is irrevocable because death results, as Justice Brennan wrote, so too is a decision to continue it, at least from the point of view of the patient. The patient’s “own degraded existence is perpetuated; his family’s suffering is protracted; the memory he leaves behind becomes more and more distorted.”¹¹⁰

Incredibly, a bill was introduced in the Ohio House in the spring of 2005 that would have made it even more likely that the preferences for treatment withdrawal of a person in a permanent vegetative state would be ignored.¹¹¹ Like Florida, Ohio’s law has for a number of years provided a list of those who might serve as surrogates and prioritized those according to the relationship with the patient—for example, placing spouse before parent.¹¹² The proposed law would have disregarded that priority in the case of surrogate designations for patients in a permanent vegetative state who had not executed an advance directive.¹¹³ Regardless of the hierarchy set out in the statute, any person among those listed in the hierarchy who would agree in writing not to withdraw artificial nutrition and hydration from a person in a permanent vegetative state would leapfrog over the others and be given the powers of the surrogate.¹¹⁴ Under this Ohio bill, what the patient herself might have wanted would not only have been subordinated to the interests of family members, it would have been rendered irrelevant.¹¹⁵ The bill’s effect would have been to nullify a

107. *Id.*

108. See Lois Shepherd, *In Respect of People Living in a Permanent Vegetative State—And Allowing Them to Die*, 16 HEALTH MATRIX (forthcoming 2006).

109. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 320 (1990) (Brennan, J., dissenting).

110. *Id.*

111. H.R. 201, 126th Gen. Assem., Reg. Sess. (Ohio 2005). As of January 7, 2006, the Bill remained in committee.

112. *Id.*

113. *Id.*

114. The person who sought to establish surrogate status in this manner would also have to agree to bear the financial burden of the continued treatment and care of the patient. *Id.* The Ohio Senate also considered something less outrageous. See S. 130, 126th Gen. Assem., Reg. Sess. (Ohio 2005) (allowing a surrogate’s decision to withdraw nutrition and hydration to be challenged by family members lower in the statutory hierarchy if the latter present some evidence that the decision is not consistent with the previously expressed intention of the patient).

115. S. 130, 126th Gen. Assem., Reg. Sess. (Ohio 2005).

patient's wishes to discontinue tube feeding by deferring to a surrogate who determined otherwise.

Throughout the Schiavo litigation, especially as the Governor of Florida became involved in defending his actions to reinsert Terri's feeding tube in 2003, concerned parties argued that the surrogate decision-making procedures established by Florida law did not adequately protect Terri's interests. In particular, the Governor and those who supported his actions charged that the decision to remove Terri's feeding tube had not been accompanied by process sufficiently protective of Terri's interest in life.¹¹⁶ Therefore, the Florida legislature considered a number of proposals in 2004 and early 2005 that would have made it more difficult to withdraw artificial nutrition and hydration from incompetent individuals. For example, one proposal required that the patient have a living will¹¹⁷ or, in the absence of a living will, that the patient have made very specific statements regarding the refusal of nutrition and hydration.¹¹⁸ The arguments by the Governor and the considerations of the legislature for more procedural protections in favor of life did not come to fruition, but if they had, they would have come at a cost to patient autonomy.

The statutory procedures currently in place for withholding or withdrawing life support have been carefully crafted to balance many interests and concerns. The right to refuse treatment was recognized in the United States only after hard-fought, bitter, tragic battles by families to release their loved ones from what they saw as imprisonment by forced medical treatment.¹¹⁹ Any changes to the statutory procedures established to effectuate that right should be subjected to thorough review and debate by appropriately convened bodies, such as a task force, composed of members with knowledge not simply of the recent *Schiavo* case, but of the history of this field of law in order to place in greater context the interests implicated. Changes to procedure designed to further safeguard a patient's interest in life (such as those advocated by Florida's Governor Bush and considered by Florida's legislature) must be approached with exceptional caution. Any additional element

116. See Petition for Writ of Certiorari, *Bush v. Schiavo*, 125 S. Ct. 1086 (2004) (contending that the preclusive effects afforded prior litigation violated Florida Governor Jeb Bush's 14th Amendment due process rights as *parens patriae*).

117. A "living will" generally denotes a written document that provides instructions regarding the continuation of life-sustaining treatment in certain conditions, such as a terminal illness or permanent vegetative state.

118. See, e.g., H.R. 701, 2005 Leg., Reg. Sess. (Fla. 2005) (proposing a presumption that health care providers provide incompetent persons nutrition and hydration to sustain life).

119. See COLBY, *supra* note 2, for a moving account of the ordeal experienced by the Cruzan family in attempting to get approval for the withdrawal of her feeding tube.

of procedure that is designed to protect a patient's interest in life is likely to diminish protection of the patient's preferences and the patient's interests other than the perpetuation of life—for example, the patient's interest in avoiding suffering. Such procedural “safeguards” or “burdens,” viewed either way, would also have effects on the family, caregivers, and health care providers that should be considered.

B. In what condition must the patient be to warrant the withdrawal of life-sustaining treatment? How certain do we have to be that the patient is in that condition? Should we treat different conditions differently when making the decision to withdraw treatment?

In 1998, when Michael Schiavo first began court proceedings to determine if his wife's feeding tube could be removed, the Schindlers did not contest the determination that their daughter was in a permanent vegetative state.¹²⁰ Beginning in 2001, however, they began to challenge that diagnosis. Ultimately, the Schindlers insisted that she was in a minimally conscious state¹²¹ and that her condition could be improved with appropriate therapy. The critical difference between a minimally conscious state and a permanent vegetative state is that the former condition involves some level of cognitive function, while there is no evidence of cognition associated with the latter.¹²²

There are a number of reasons why it became important for the Schindlers to challenge the diagnosis of permanent vegetative state.

120. Cerminara, *supra* note 38. Cerminara points out that the Schindlers did not argue that Terri was not in a permanent vegetative state until 2001. Before that time, their argument against removal of the feeding tube was that Michael Schiavo was not accurately representing their daughter's wishes. See also WOLFSON REPORT, *supra* note 14, at 33 n.1 (noting that “until recently” the Schindlers agreed Terri was in a persistent vegetative state).

121. The criteria for diagnosing the minimally conscious state, as recently developed by a group of experts, are as follows:

Evidence of limited but clearly discernible self or environmental awareness on a reproducible or sustained basis, by one or more of these behaviours:

1. Simple command following
2. Gestural or verbal ‘yes/no’ responses (regardless of accuracy)
3. Intelligible verbalization
4. Purposeful behaviour including movements or affective behaviours in contingent relation to relevant stimuli; examples include:
 - (a) appropriate smiling or crying to relevant visual or linguistic stimuli
 - (b) response to linguistic content of questions by vocalization or gesture
 - (c) reaching for objects in appropriate direction and location
 - (d) touching or holding objects by accommodating to size and shape
 - (e) sustained visual fixation or tracking as response to moving stimuli.

JENNETT, *supra* note 1, at 24.

122. See *supra* note 1 (describing the permanent vegetative state).

First, if Terri Schiavo had some consciousness, even of a minimal sort, then she would have had some interest in living because she could have experienced that life, at least in some way.¹²³ Moreover, if the Schindlers could have argued credibly that their daughter's condition had improved over time, this would have suggested that she could continue to improve in the future with proper therapy. Either some existing consciousness or some potential for future consciousness would have called into question the court's earlier determination that Terri Schiavo would not want to continue living in a permanent vegetative state. That earlier determination would have needed reexamination and perhaps reversal.

Second, the Schindlers' claim that their daughter was not, or was no longer, in a permanent vegetative state was important in garnering public support for their cause to continue her life support. The videotapes repeatedly shown on television and the Internet did indeed, in their shortened form of thirty seconds or so, appear to show a person responding to her mother's presence.¹²⁴ Terri Schiavo appeared in those video segments to be severely disabled, but not completely unconscious. The characterization of Terri as a person with a severe disability evoked social impulses to protect her from prejudice, from discrimination, from ostracism, from abuse, from the sort of "euthanasia" practiced by repressive regimes such as Nazi Germany.¹²⁵ A substantial portion of prominent disability rights groups took up her cause under these themes.¹²⁶

123. A number of commentators have noted that individuals in a permanent vegetative state or otherwise permanently unconscious lack any current or future interests in living because of their lack of sentience. This lack of interests is unique; those who have some ability to experience life, however minimal, cannot be said to completely lack any interest in life. ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 126–29 (1989); Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 *ARIZ. L. REV.* 373, 378 (1986).

124. The video is still available on a number of websites. See, e.g., <http://www.cnsnews.com/Culture/Archive/200310/CUL20031014c.html> (last visited Jan. 13, 2006).

125. See Cathy Young, *The Rhetoric in Schiavo Case*, *BOSTON.COM NEWS*, Mar. 26, 2005, http://www.boston.com/news/globe/editorial_opinion/oped/articles/2005/03/26/the_rhetoric_in_schiavo_case; See also *Scarborough Country* (MSNBC television broadcast Dec. 2, 2004) (transcript available at 2005 WLNR 4815744) (with guest appearance by Terry Randall, described as "Schindler family spokesperson and founder of Operation Rescue," associating the removal of Terri Schiavo's feeding tube with the deaths of innocent people killed by Nazis).

126. See Stephen Nohlgren & Tom Zucco, *Schiavo Case Has Myriad Fund Sources*, *ST. PETERSBURG TIMES*, Mar. 28, 2005, at 1A. Examples of those who supported the Schindlers are the Alliance Defense Fund, Life Legal Defense Foundation, RightMarch, the Family Research Council. *Id.* Twenty-one national disability rights organizations signed a letter in October of 2003 in support of the continued feeding of Terri Schiavo; the letter compared Terri's situation with that of persons with Down's syndrome, autism, and ALS. *Terri Schindler-Schiavo and*

Most important as a legal matter, however, if Terri Schiavo was in a minimally conscious state rather than a permanent vegetative state, she would not have fallen into one of the three conditions that the Florida statute provides are conditions in which a proxy can withdraw life-sustaining treatment. Those three conditions are: a terminal condition,¹²⁷ an end-stage condition (such as advanced Alzheimer's),¹²⁸ or a persistent vegetative state. Two physicians must verify the existence of the condition.¹²⁹

State statutes regarding end-of-life decision making are of a curious nature. Essentially they provide procedures, which if followed, confer immunity from liability for those involved in treatment withdrawal as long as they act in good faith.¹³⁰ They also provide procedures and

Disability Rights, Oct. 27, 2003, TheArcLink.org, <http://www.thearc.org/news/article.asp?ID=623>. The letter stated that the "life-and-death issues surrounding Terri Schindler-Schiavo are first and foremost disability rights issues" and "Terri Schindler-Schiavo's fate is entwined with all disabled people who rely on surrogates." *Id.*

127. A "terminal condition" means "a condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death." FLA. STAT. § 765.101(17) (2004).

128. An "end-stage condition" is "an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective." FLA. STAT. § 765.101(4) (2004). This term is commonly understood to embrace advanced dementia, such as that caused by Alzheimer's, which is "'steadily progressive,' incurable, and ultimately fatal." *See* 85 Op. Md. Att'y Gen. 33 (2000) (quoting LAWRENCE J. TIERNEY, JR. ET AL., CURRENT MEDICAL TREATMENT & DIAGNOSIS 55 (39th ed. 2000)) (interpreting a statute similar to Florida's).

129. FLA. STAT. § 765.306 (2004).

130. It is difficult, however, to make generalizations about such statutes. As the Prefatory Note to the Uniform Health Care Decisions Act of 1993 states:

[A] majority of states have statutes allowing family members, and in some cases close friends, to make health-care decisions for adult individuals who lack capacity. This state legislation, however, has developed in fits and starts, resulting in an often fragmented, incomplete, and sometimes inconsistent set of rules. Statutes enacted within a state often conflict and conflicts between statutes of different states are common.

UNIF. HEALTH CARE DECISIONS ACT, 9 U.L.A. 84-85, prefatory note (2005). According to Meisel and Cerminara:

The primary purpose of these statutes is to make clear what is at least implicit in the case law: that the customary medical professional practice of using family members to make decisions for patients who lack decisionmaking capacity and who lack advance directives is legally valid, and that ordinarily judicial proceedings need not be initiated for the appointment of a guardian.

MEISEL & CERMINARA, *supra* note 3, § 8.01. *See, e.g.*, FLA. STAT. § 765.109 (2004) (conferring immunity on those who in good faith carry out decisions made under the statute); N.C. GEN. STAT. § 90-322(d) (2003) (conferring immunity in connection with the withholding or discontinuance of life-sustaining treatment in accordance with the statute); OHIO REV. CODE ANN. § 2133.11 (2005) (conferring immunity on physicians who withhold treatment in accordance with the statute).

standards for courts to follow in approving decisions to withdraw treatment which come before them and which allow family members who are not proxies to challenge the decisions of those who are proxies.¹³¹

Generally, such statutes do not explicitly limit treatment-withdrawal decisions to the situations described in the statute. For example, Florida's statute does not state that artificial nutrition and hydration *cannot* be withdrawn from someone in a minimally conscious state.¹³² Instead, it states when treatment *can* be withdrawn.¹³³ It also explicitly preserves the common law and constitutional rights of patients,¹³⁴ although, of course, a statutory recognition of the preservation of constitutional rights is not necessary.

In Terri Schiavo's situation, it is not clear what effect a diagnosis of minimal consciousness as opposed to permanent vegetativeness would have had on the resolution of the case. The circuit court determined, prior to its 2000 order authorizing the discontinuance of the feeding tube, that Terri Schiavo was in a permanent vegetative state.¹³⁵ A second hearing was later required by the appellate court when the Schindlers claimed that there was new evidence regarding medical treatments that could improve their daughter's condition.¹³⁶ Although the Schindlers offered two physicians' testimony that Terri Schiavo's condition might be something other than a permanent vegetative state at this second hearing, the circuit court found the testimony of the other three physicians more persuasive.¹³⁷ Nevertheless, it is not even clear from the circuit court's opinion whether a different diagnosis would

131. See, e.g., FLA. STAT. § 765.105 (2004) (allowing family members and other interested parties to seek expedited judicial intervention to review a proxy's decision); OHIO REV. CODE ANN. § 2133.08(E)(1) (2005) (allowing objection by certain family members of proxy's decision and subsequent judicial review).

132. Health Care Advance Directives, FLA. STAT. §§ 765.101–546 (2004).

133. FLA. STAT. § 765.404 (2004). This statute provides that for patients in a persistent vegetative state, life-prolonging procedures may be withheld or withdrawn when:

(1) The person has a judicially appointed guardian representing his or her best interest with authority to consent to medical treatment; and (2) The guardian and the person's attending physician, in consultation with the medical ethics committee of the facility where the patient is located, conclude that the condition is permanent . . . and that withholding or withdrawing life-prolonging procedures is in the best interest of the patient.

Id.

134. FLA. STAT. § 765.106 (2004).

135. Schiavo Original 2000 Order, *supra* note 4, at 6.

136. *Schiavo III*, 800 So. 2d 640, 643 (Fla. Dist. Ct. App. 2001).

137. *In re Schiavo*, No. 90-2908-GB-003, 2002 WL 31817960, at *3 (Fla. Cir. Ct. Nov. 22, 2002).

have caused the court to change its mind about the propriety of removing the feeding tube.¹³⁸ The court wrote that the real issue was not whether Terri Schiavo was in a permanent vegetative state (although it found the evidence overwhelmingly supportive of that view), but whether treatment options would “significantly improve her quality of life.”¹³⁹ Finding that there was no evidence to that effect, much less a preponderance of the evidence, the court reaffirmed its original decision that the feeding tube should be withdrawn.¹⁴⁰

If the court had found the evidence of the physicians chosen by the Schindlers to be convincing—in other words, found that Terri Schiavo was in something other than a true permanent vegetative state—and still determined that she would not want to continue being tube fed in that condition, then it would not have been following the procedures and standards set forth in the Florida statute. But it would still have been acting within its authority in making that decision, and, in fact, Terri Schiavo’s constitutional rights might have required that determination. The Florida Supreme Court in *In re Browning* clearly stated that the condition of the patient is not a factor that limits the patient’s right to refuse medical treatment.¹⁴¹ In that case, the court approved a surrogate’s decision to withdraw a feeding tube from a woman whose death was not “imminent” and who was not in a permanent vegetative state, the two conditions at that time included in the Florida statutes for which a surrogate could withdraw life-prolonging treatment.¹⁴²

It is not clear what the future holds with respect to the legal treatment of people in a minimally conscious state. Those who argued that Terri Schiavo was in a minimally conscious state sought to characterize her condition as one of severe disability, with the implicit assumption that such individuals should be treated differently from those in a permanent vegetative state. As a general matter, state statutes do not currently sanction decisions to withdraw treatment from such individuals, and this may suggest that treatment withdrawal in such instances is not proper unless the treatment is burdensome to the patient. Yet under state constitutions and the Federal Constitution, the question is open. Could states *prohibit* treatment withdrawal in such instances? *In re Browning* indicates that Florida’s constitution, at least, would not allow such a statutory prohibition.¹⁴³ Even the U.S. Constitution might protect the

138. *Id.* at *4–5.

139. *Id.* at *3 (referring to the standard set by the District Court of Appeals in *Schiavo III*).

140. *Id.* at *5.

141. *In re Browning*, 568 So. 2d 4, 10 (Fla. 1990).

142. *Id.* at 9.

143. *See id.* at 10 (holding that a patient has a right to refuse treatment irrespective of his or

right of individuals to have the option of treatment withdrawal in such instances if they indicated, when competent, their preferences for treatment withdrawal in such circumstances.¹⁴⁴ Nevertheless, state legislatures or courts may be able to impose higher procedural standards for withdrawing treatment in such instances.¹⁴⁵ The state's interest in protecting vulnerable individuals from harm and in protecting the individual's own continued interest in living a life that she can in some way experience (as opposed to the patient in a permanent vegetative state) may be sufficiently weighty to justify, as a constitutional matter, higher procedural safeguards, in accordance with the Supreme Court's holding in *Cruzan*.¹⁴⁶ Respect for the individual's bodily integrity and autonomy rights, however, should preclude an outright prohibition against treatment withdrawal for the minimally conscious who at one time possessed competency. The fact that higher procedural requirements might be constitutionally permissible does not, of course, answer the question whether such requirements would make good policy.

One final point about the minimally conscious state should be noted. Many states provide a form living will for residents of the state to follow, if they wish, to document their choices about the provision of life-sustaining treatment in the event of later incompetence.¹⁴⁷ In Florida, that form offers individuals the option of treatment refusal in the same three conditions that must be present for a proxy to withdraw treatment under the statute.¹⁴⁸ It does not, therefore, list "minimally conscious state" as one of the conditions in which a prior preference regarding treatment might be documented. But if individuals have a

her medical condition).

144. See generally *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990). *Cruzan* assumed that competent individuals have a right to reject unwanted medical treatment that is not lost in the event of later incompetence. See *supra* note 3 (inferring a constitutional right to refuse life-sustaining medical treatment).

145. Kathy Cerminara has suggested that stronger evidence of a patient's preferences to refuse treatment might be warranted for those in a minimally conscious state. Cerminara, *supra* note 38 (manuscript on file with author).

146. In this regard, note the California case, *In re Wendland*, 28 P.3d 151 (Cal. 2001) finding that conservator failed to prove by clear and convincing evidence that the conservatee—who was severely brain damaged but not permanently vegetative—wished to refuse life-sustaining treatment or that to withhold such treatment would have been in his best interest. In that case, the court stated, "It is . . . worth mentioning that no decision of which we are aware has approved a conservator's or guardian's proposal to withdraw artificial nutrition and hydration from a conscious conservatee or ward." *Id.* at 170.

147. MEISEL & CERMINARA, *supra* note 3, § 7.05[B].

148. FLA. STAT. § 765.303 (2004). A person may elect to withhold treatment if: (1) he or she has a terminal condition; (2) has an end-state condition; or (3) is in a persistent vegetative state. *Id.*

common law and/or constitutional right to have treatment withdrawn in conditions that are not listed in the statutory form (like the minimally conscious state), then the form is misleading and unnecessarily limited. It is entirely possible that a number of people who wish to execute a living will would not want to be kept alive for fifteen years in a minimally conscious state. Yet if a person's living will specifies certain conditions in which treatment should be withdrawn and does not specify others, the living will might actually be used as evidence that the person did not want treatment withdrawn in a minimally conscious state, when actually the form provided by the state simply addressed certain conditions and not others.¹⁴⁹ Statutory forms that limit treatment withdrawal to certain narrow physical conditions are poor tools for effectuating individual choice in end-of-life decision-making. If lawmakers are going to champion the living will as the sort of proof that will suffice to avoid a controversy like that over Terri Schiavo—and they have—then people need to be given an easy and inexpensive way to protect themselves against forced treatment in the conditions in which they would like to reject it.¹⁵⁰ Similarly, hospital policies on the withdrawal of life support also merit review following our collective consciousness-raising about the minimally conscious state. Do they, like the living will forms, mirror the limited statutory standards for the refusal of life support? If so, they also merit reconsideration.

C. Should there be stricter rules for withdrawing feeding than other forms of treatment?

The fact that the treatment withdrawn from Terri Schiavo was artificial nutrition and hydration rather than a ventilator or other form of medical treatment held great significance for many people. Even

149. A similar problem arose in the case of *Wright v. Johns Hopkins Health Sys. Corp.*, 728 A.2d 166 (Md. 1999). There, a man living with AIDS had executed a living will in accordance with the end-of-life decision-making statute in effect at the time. *Id.* at 175. The living will therefore specified that it would take effect when two physicians had determined that his death was imminent (then the only condition covered by the statute). *Id.* The court reasoned that the living will could not take effect in the event of any other condition. *Id.* Although the living will statute had since been modified to include other conditions (terminal condition, persistent vegetative state, end-stage condition), the living will was governed, and therefore limited, by its own terms. *Id.*

150. An example may be forms that describe the kinds of human interactions or sensations a patient may find critically important for enjoyment or meaning of life and the permanent absence of which the patient would find intolerable. There may, however, simply not be a way to document many of these choices effectively, both because of the difficulty of predicting in advance what one would want and the limits of drafting in advance for the complex situations that actually come to pass. See Fagerlin & Schneider, *supra* note 106, at 30–42 (describing the inadequacies of living wills).

though Terri Schiavo would not experience the lack of nutrition and hydration upon removal of her feeding tube, protestors charged that she was being “starved” to death.¹⁵¹ Even supposedly objective newscasters adopted this highly charged language of starvation, carrying with it the clear implication that Terri Schiavo was being deprived of care, that she was being neglected and abused.¹⁵² In many ways, those who protested the removal of her feeding tube did so primarily not because they believed that Michael Schiavo was misrepresenting his wife’s wishes or that Terri Schiavo was minimally conscious, but because they believed that feeding should never be withdrawn from a patient unless it is burdensome. To fail to feed is to fail to care, on this view, and is an unacceptable way for human beings to treat one another.

The Florida legislature responded to these concerns in the spring of 2004 and 2005. In those legislative sessions, the Florida State House of Representatives and Senate considered various versions of a bill that would add procedural hurdles for the withdrawal of artificial nutrition and hydration by a proxy for an incompetent patient. Under the proposed legislation, a proxy could only withdraw artificial nutrition and hydration if the patient had a living will directing that it be withdrawn in the situation that eventuated or had made very specific oral directives that would satisfy the legal notion of informed consent.¹⁵³ The title of the original bill reveals its bias: the Starvation

151. *Mom Makes Plea to Save Daughter; Congress Move Could Reinstate Feeding Tube for Terri Schiavo*, TORONTO STAR, Mar. 20, 2005, at A02 (describing protestors symbolically attempting to bring food and water to Terri Schiavo outside her hospice); *Terri Schiavo, 41, Dies* (CNN television broadcast Mar. 31, 2005) (transcript available at 2005 WLNR 5042450) (featuring video clip of Rep. Tom DeLay stating, “A young woman in Florida is being dehydrated and starved to death.”).

152. *FOX on the Record with Greta Van Susteren, Terri Schiavo Case Inciting Passionate and Desperate Measures* (FOX News television broadcast Mar. 26, 2005) (transcript available at 2005 WLNR 4766040).

In fact, the Schindlers in a court filing urging that a guardian ad litem be allowed to oversee swallowing tests and therapy for Terri Schiavo, invoking a Florida statute providing that it is a felony to withhold food from a disabled or vulnerable adult. Petitioners’ Response to Court’s Request Regarding Guardian ad Litem, *In re Schiavo*, No. 90-2908GD-003 (Fla. Cir. Ct. Jan. 5, 2004). See FLA. STAT. § 825.102(3)(a)(1) (2004), which in certain circumstances makes neglect of an elderly or disabled adult a felony and defines neglect to include:

A caregiver’s failure or omission to provide an elderly person or disabled adult with the care, supervision, and services necessary to maintain the elderly person’s or disabled adult’s physical and mental health, including, but not limited to, food, nutrition, clothing, shelter, supervision, medicine, and medical services that a prudent person would consider essential for the well-being of the elderly person or disabled adult.

Id.

153. The bill proposed in Spring 2004, for example, required that for artificial nutrition and

and Dehydration of Persons with Disabilities Prevention Act.”¹⁵⁴ Interest in this topic remains high in Florida (although neither legislative session passed the proposed bill) and in other states, some of which have considered similar legislation in the wake of the Schiavo controversy.¹⁵⁵ The fact that Pope John Paul II, in spring 2004, also

hydration to be withdrawn in the absence of a written directive by the patient, there had to be clear and convincing evidence that the incompetent person, when competent, gave “express and informed consent” to withdrawing or withholding nutrition or hydration in the applicable circumstances. The incompetent person must have expressed a desire to have treatment withdrawn in the same kind of circumstances in which the person later finds herself. Moreover, the “express and informed consent” that is required means that the person, when expressing a desire to have nutrition and hydration withdrawn, had general knowledge of the procedure contemplated, the available alternatives to the procedure, and knowledge of the medical condition under which the treatment would be withdrawn. S.B. 692, 2004 Leg., Reg. Sess. (Fla. 2004).

154. *Id.*

155. The following states have proposed similar bills: Alabama Starvation and Dehydration of Persons With Disabilities Prevention Act, H.B. 592, 2005 Reg. Sess. (Ala. 2005); Hawaii Starvation and Dehydration of Persons With Disabilities Prevention Act, H.B. 1577, 23d State Leg. (Haw. 2005); Iowa Starvation and Dehydration of Persons With Disabilities Prevention Act, H. Study B. 302, 81st Gen. Assem., 1st Sess. (Iowa 2005); H.B. 501, 2005 Reg. Sess. (Ky. 2005); Human Dignity Act, S.B. 40, 31st Reg. Sess. (La. 2005); Presumption of Nutrition and Hydration Sufficient to Sustain Life, S. File 2184, 84th Leg. Sess., 1st Reg. Sess. (Minn. 2005); Presumption of Nutrition and Hydration Sufficient to Sustain Life Act, H.B. 905, 93d Gen. Assem., 1st Reg. Sess. (Mo. 2005); S.B. 4083, 228th Ann. Leg. Sess. (N.Y. 2005); North Carolina Disabled Persons Protection Act, H.B. 1175, Gen. Assem., Sess. 2005 (N.C. 2005); S.B. 130, 126th Gen. Assem., Reg. Sess. (Ohio 2005). Several of these bills (Alabama’s, Hawaii’s, Iowa’s, Minnesota’s, and North Carolina’s) are modeled on an act proposed by the National Right to Life Committee, called the “Model Starvation and Dehydration of Persons with Disabilities Prevention Act.” Press Release, National Right to Life Committee Spurred by Schindler-Schiavo Case, Model State Law to Prevent Starvation and Dehydration Proposed, *available at* <http://www.nrlc.org/euthanasia/ModelBillAnnoucement.html> (last visited Jan. 13, 2006) [hereinafter NRLC Press Release]. The model law proposed by the National Right to Life Committee creates a presumption that those incapable of making health care decisions would wish to receive food and fluids so long as their provision is medically possible, would not itself hasten death, and can be ingested or absorbed so as to sustain life. NAT’L RIGHT TO LIFE COMM., MODEL STARVATION AND DEHYDRATION OF PERSONS WITH DISABILITITES PREVENTION ACT (Revised 2006), <http://www.nrlc.org/euthanasia/modeln&hstatelaw.pdf> [hereinafter NRLC MODEL STATE LAW]. The presumption would not apply in cases where the person has specifically authorized the withholding or withdrawal of nutrition and hydration in an appropriate legal document, such as an advanced directive, or where there is clear and convincing evidence that the person gave express and informed consent to the rejection of food and fluids. *Id.* The definition of “express and informed consent” requires that the patient have understanding of the procedure to provide artificial nutrition and hydration, the risks and hazards of the procedure, and alternatives.” *Id.* This definition is so restrictive that the NRLC’s proposal would virtually require a writing in every instance. Indeed, the sponsors of the model act probably intend that result—to require a writing. The proposal allows for the possibility that oral evidence can meet the clear and convincing evidence because of concerns that it otherwise would not pass constitutional scrutiny. NRLC Press Release, *supra*. To meet the standard in the model law, the oral evidence would have to show that a patient like Terri Schiavo understood what a persistent vegetative state was and how artificial nutrition and hydration was medically provided. NRLC MODEL STATE LAW, *supra*. This is a level of understanding that we would certainly expect from a surrogate before making a present decision to continue or refuse artificial nutrition and

spoke on the importance of continuing artificial feeding of people in a permanent vegetative state adds to the likelihood that this will continue to be an issue.¹⁵⁶ The Pope announced that nutrition and hydration must be considered “basic care” that cannot be removed unless the benefits of such removal outweigh the burdens, an announcement that prompted Catholic health care systems to begin reviewing their policies in regard to the feeding of patients in a permanent vegetative state.¹⁵⁷

I would like to suggest two primary ways of addressing the question whether it should be more difficult to withdraw artificial feeding from incompetent patients than other treatments. The first approach is to consider whether stricter rules for withdrawing artificial feeding can be justified under our current understanding of the right to refuse treatment protected by the U.S. Constitution and many state constitutions. According to the clear consensus of courts, competent individuals have a right to refuse artificial nutrition and hydration and do not lose that right when they become incompetent.¹⁵⁸ Clearly, the legislation proposed in Florida and other states, and the model act proposed by the National Right to Life Committee upon which many of these state efforts are based,¹⁵⁹ attempt to work within the parameters set out in those cases. The proposed legislation does not treat the provision of artificial nutrition and hydration differently from other medical treatments when *competent* patients are involved, but does treat it differently for *incompetent* patients.¹⁶⁰ The legislation also does not restrict legal recognition of living wills that clearly reject artificial nutrition and hydration. Instead, the proposed legislation appears (at least) designed to insure that artificial feeding is not withdrawn against the patient’s wishes in those cases in which there is an incompetent

hydration for such a patient, but it is not the sort of understanding that courts have generally insisted upon patients having prior to incompetency in order for their preferences about treatment withdrawal in a permanent vegetative state to be honored.

156. Manuel Roig-Franzia, *Catholic Stance on Tube-Feeding is Evolving*, WASH. POST, Mar. 27, 2005, at A7.

157. At the time, the practice of Catholic hospitals in the United States had been to allow family members more discretion to withdraw artificial nutrition and hydration for patients in a permanent vegetative state. Leonard J. Nelson, III, *Catholic Bioethics and the Case of Terri Schiavo*, 35 CUMB. L. REV. 543, 544–45 (2005). This was permitted under the more general policy that artificial nutrition and hydration can be withdrawn from incompetent patients when continued treatment is burdensome to the patient or the patient’s family. *Id.* at 556–57.

158. *See, e.g., In re Browning*, 568 So. 2d 4, 11–12 (Fla. 1990) (citing cases regarding the right to refuse artificial nutrition and hydration); *see also* Rasmussen *ex rel. Mitchell v. Fleming*, 741 P.2d 674 (Ariz. 1987) (explaining that the right of privacy and the doctrine of informed consent gave the patient the right to refuse medical treatment).

159. NRLC MODEL STATE LAW, *supra* note 155.

160. *See id.* (addressing only decisions to withhold or withdraw nutrition and hydration from a person “legally incapable of making health care decisions”).

patient and no clear written directive.¹⁶¹ As will become clear shortly, however, I think we cannot justify stricter requirements for artificial feeding relative to requirements for other forms of medical treatment in the name of promoting the accuracy of surrogate reflections of patient preferences.

The second approach in considering this question is to ask whether the courts have been correct in finding that artificial nutrition and hydration is similar to other medical treatments that can be withdrawn upon competent evidence of the patient's preferences. It is important to consider this approach because, again, much of the protest over the removal of Terri Schiavo's feeding tube was about feeding itself, rather than a concern that her wishes were misrepresented. Courts do not now appear inclined to change course on this issue, but the potential for more vitalist¹⁶² or conservative judges in the future makes this a question that cannot be ignored. Though in some ways reviewing this issue covers old ground that was debated thoroughly in the 1980s and 1990s,¹⁶³ I want to suggest that a little-noticed aspect of the Schiavo controversy—the suggestion that Terri Schiavo might be fed by hand—may present some new ways of looking at the issue.

1. Can stricter procedural requirements for the removal of artificial feeding be justified within the context of a constitutional right to refuse artificial feeding?¹⁶⁴

Recent efforts to restrict the ability of surrogates to withdraw nutrition and hydration from patients reflect a break in the consensus that has developed over the past twenty-five years in medical and legal communities. That consensus had held that artificially provided

161. *See id.* (under proposed model law, presumption in favor of feeding is inapplicable when a person has executed a directive in accordance with state advance directive statutes).

162. *See* Stacey A. Tovino & William J. Winslade, *A Primer on the Law and Ethics of Treatment, Research, and Public Policy in the Context of Severe Traumatic Brain Injury*, 14 ANNALS HEALTH L. 1, 27 (2004) (defining "vitalism" as "the value system that holds that any human life is precious and should be biologically prolonged as long as possible and at any cost"); *see also* Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 442–43 (1988) ("A vitalist believes that life, in and of itself, is a good worth preserving."); *see generally* Alicia R. Ouellette, *When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L.J. 1 (2004) (arguing against a vitalist approach).

163. *See generally* BY NO EXTRAORDINARY MEANS: THE CHOICE TO FORGO LIFE-SUSTAINING FOOD AND WATER (Joanne Lynn, M.D. ed. 1990) (compiling several academic articles dealing with all aspects of the debate).

164. Portions of this section of the article appear in similar form in Lois Shepherd, *Changing the Rules on Withdrawing Nutrition and Hydration: From "Terri's Law" to the "Starvation and Dehydration" Bill*, 11 FLA. B. PUB. INT. L. SEC. REP. 1 (April 2004).

nutrition and hydration should be treated in the same manner as other forms of medical treatment.¹⁶⁵ As the Florida Supreme Court wrote in *In re Browning*:

We conclude that a competent person has the constitutional right to choose or refuse medical treatment, and that right extends to all relevant decisions concerning one's health. Courts overwhelmingly have held that a person may refuse or remove artificial life-support, whether supplying oxygen by a mechanical respirator or supplying food and water through a feeding tube. We agree and find no significant legal distinction between these artificial means of life-support.¹⁶⁶

Reflecting this consensus, many state statutes expressly place artificially provided nutrition and hydration on par with other forms of medical treatment, like ventilators and dialysis, which may in appropriate circumstances be withdrawn from patients, including those who have lost competency.¹⁶⁷

As *Cruzan*, *Browning*, and numerous court decisions from other states have determined, the right to refuse treatment is not lost by virtue of incapacity or incompetence.¹⁶⁸ Rather, the question is what procedures must be followed to determine that the decision made regarding continued treatment is the one the incompetent individual would choose for herself if she could. A state may impose procedural requirements to safeguard this "personal element" of an individual's choice between life and death.¹⁶⁹ Accordingly, the Supreme Court in the *Cruzan* decision upheld Missouri's law requiring clear and convincing evidence of Nancy Cruzan's wishes before allowing her feeding tube to be removed.¹⁷⁰ Florida's existing end-of-life statutes similarly require that when a proxy makes a decision to withdraw life-prolonging procedures for another that he do so on the basis of clear and

165. See MEISEL & CERMINARA, *supra* note 3, § 6.03[G][4] (reporting the "virtual unanimity among appellate courts permitting the forgoing of medically supplied nutrition and hydration").

166. *In re Browning*, 568 So. 2d 4, 11–12 (Fla. 1990).

167. See, e.g., N.C. GEN. STAT. § 90-322(a) (2003) (expressly allowing the withdrawal or withholding of artificial nutrition and hydration from a permanently comatose individual who is terminally ill or in a persistent vegetative state); VA. CODE ANN. § 54.1-2982 (2004) (including artificial nutrition and hydration in the definition of life-prolonging procedures that may be withheld or withdrawn by a surrogate decision-maker under VA. CODE ANN. § 54.1-2986 (2004)).

168. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990); *In re Browning*, 568 So. 2d 4, 10 (Fla. 1990).

169. *Cruzan*, 497 U.S. at 281 ("We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements.").

170. *Id.* at 282.

convincing evidence of the affected individual's wishes.¹⁷¹

As noted above, a number of proposals in various state legislatures in the spring of 2005 would have imposed special procedural requirements that a proxy¹⁷² would have to satisfy before withdrawing nutrition and hydration from an incompetent patient but would not have made it more difficult to remove artificial feeding if the patient was competent or had executed a clearly drafted, specific living will.¹⁷³ The supporters of such statutory changes appeared interested in imposing stricter standards out of a concern that proxies may be more likely to misunderstand or misrepresent the decision an incompetent person would make about nutrition and hydration than a decision such a person would make about other life-sustaining treatments. In fact, the bias of these proposals suggests that the concern was that nutrition and hydration would be withdrawn contrary to the wishes of the patient.

Legislative proposals imposing stricter requirements for withholding or withdrawing tube feeding likely have it backwards, however. Proxies are more likely to insert or continue a feeding tube for a patient when that is *not* what the patient would want.¹⁷⁴ As we witnessed with the Schindlers, family members often state that they cannot let a relative "starve to death."¹⁷⁵ Many proxies are already biased toward the provision of nutrition and hydration because of their own perceived role in caring for their relative or loved one or because of their religious beliefs that sustenance should never be withheld.¹⁷⁶ Some family member proxies, for example, may seem less concerned with what their relative may have wanted and more concerned with what they feel are their duties as caregivers and members of religious faiths.¹⁷⁷

171. FLA. STAT. § 765.401(3) (2004).

172. Note that under the Florida bill, these restrictions would also apply to a person designated in an advance directive to make such decisions unless the advance directive specifically authorized the withdrawal of nutrition and hydration in the applicable circumstances. H.B. 701, 2005 Leg., Reg. Sess. (Fla. 2005).

173. See *supra* note 155 (referring to these legislative proposals).

174. See generally Orentlicher & Callahan, *supra* note 42, at 395–99 (reviewing studies that show: feeding tubes are often used when they do not benefit the patients who receive them; physicians are more reluctant to forego feeding tubes for patients than other forms of life-sustaining treatment; and family members often feel left out of the decision-making process and that they have no alternative but to consent to tube feeding).

175. Muriel R. Gillick, *Rethinking the Role of Tube Feeding in Patients with Advanced Dementia*, 342 NEW ENG. J. MED. 206–10 (2000) (discussing family members' views of feeding tubes for patients with advanced dementia).

176. *Id.* at 208.

177. For example, in a report filed with the court, the guardian ad litem appointed under Terri's Law related that in previous hearings, Schindler family members had stated their desire to keep Terri alive under a number of "[n]early gruesome" scenarios. WOLFSON REPORT, *supra*

There does not appear to be any solid basis for believing that most proxies will seek to withdraw or withhold a feeding tube when the patient for whom they speak would wish otherwise. A number of studies reveal that a very high percentage of people, eighty-five percent or higher, would wish to refuse a feeding tube if they were in a permanent vegetative state, an end-stage condition, or suffered severe brain damage.¹⁷⁸ Moreover, recent studies show that while family members tend to authorize a feeding tube for patients with advanced dementia, they later regret that decision as it becomes burdensome to the patient.¹⁷⁹ Such patients often pull out their feeding tubes unless they are physically restrained.¹⁸⁰ Studies also indicate that feeding tubes may not even extend the lives of these patients.¹⁸¹ These same family members say they would not want a feeding tube if they found themselves in similar circumstances.¹⁸² In a study of randomly selected, competent nursing home residents, only one third said they would want a feeding tube if they became unable to eat because of permanent brain damage.¹⁸³ This number of positive responses was reduced by a fourth when the participants learned that they might need to be physically restrained to accommodate the feeding tube, and would likely be even smaller if they had been informed about growing

note 14, at 17. For example, they were asked whether they would agree to forego open heart surgery for Terri if she had had all four limbs amputated because of gangrene. *Id.* They responded that the surgery should be done. *Id.* The guardian ad litem relates, "Within the testimony, as part of the hypotheticals presented, Schindler family members stated that even if Theresa had told them of her intention to have artificial nutrition withdrawn, they would not do it." *Id.*

178. Brennan's dissent in the *Cruzan* case cites a Colorado University Graduate School of Public Affairs study in which 85% of those people questioned answered that they would not want a feeding tube if they became permanently unconscious. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 312 n.11 (Brennan, J., dissenting).

179. Guido M.A. Van Rosendaal, M.D. & Marja J. Verhoef, Ph.D., Correspondence, *Difficult Decisions for Longterm Tube-Feeding*, 161(7) CANADIAN MED. ASS'N J. 798, 798 (Oct. 5, 1999); see also Howard Brody, M.D., Ph.D. et al., *Withdrawing Intensive Life-Sustaining Treatment—Recommendations for Compassionate Clinical Management*, 336 NEW ENG. J. MED. 652, 652 (Feb. 27, 1997) (describing some of the discomforts and burdens of artificially provided nutrition and hydration).

180. Joanne Lynn & James F. Childress, *Must Patients Always Be Given Food and Water?*, 13 HASTINGS CENTER REP. 17, 18 (Oct. 1983).

181. See Orentlicher & Callahan, *supra* note 42, at 389–97 (citing and discussing studies that show that many patients do not benefit from feeding tubes in terms of improvement in the quality or length of their lives).

182. Van Rosendaal & Verhoef, *supra* note 179, at 798.

183. Gillick, *supra* note 175, at 208 (citing Linda A. O'Brien et al., *Nursing Home Residents' Preferences for Life-Sustaining Treatments*, 274 J. AM. MED. ASS'N 1775, 1775–79 (1995) and Linda A. O'Brien et al., *Tube Feeding Preferences Among Nursing Home Residents*, 12 J. GEN. INTERNAL MED. 364, 364–71 (1997) [hereinafter O'Brien]).

evidence of the lack of efficacy of such tubes for patients with dementia.¹⁸⁴

What about the charge that dying of dehydration is painful? On the surface, this might be a reason to treat nutrition and hydration differently than other life-prolonging treatments, because the present interests of the patient would be in conflict with her previously formed preferences. Of course, dying in this way would not be painful at all to someone in a permanent vegetative state like Terri Schiavo, who could not feel pain or even experience thirst or hunger.¹⁸⁵ Dying by dehydration for someone who is terminally ill or in an end-stage condition also does not appear to be experienced negatively. There are numerous reports that such patients do not experience much, if any, discomfort.¹⁸⁶ Hospice nurses report that patients who stop eating or drinking experience a comfortable and peaceful death.¹⁸⁷ Any thirst the patients might experience is relieved by the use of ice chips and mouth swabs.¹⁸⁸ In any event, to justify closer scrutiny of decisions to withdraw nutrition and hydration on this basis, we would need evidence (which we do not have) that dying of dehydration is more painful than dying from the withdrawal of other life-prolonging treatments—more painful, for example, than dying of untreated pneumonia or respiratory, cardiac, or renal failure.

Stricter evidentiary and procedural standards for the withdrawal and withholding of nutrition and hydration are not likely to better elicit and preserve the actual preferences of the patient and therefore do not appear to be valid on that basis. Stricter restrictions on proxy decision making for nutrition and hydration would mean that the wishes of the incompetent patient would be less likely, rather than more likely, to be honored, with especially profound consequences for someone in a permanent vegetative state, whose life may be extended for decades against her wishes.

2. Feeding as Basic Care

Is concern for patient preferences really at the heart of proposals to make it more difficult for proxies to withhold or withdraw feeding from their loved ones? There is very good reason to believe that, instead,

184. O'Brien, *supra* note 183, at 366.

185. Task Force Report, *supra* note 19, at 1572.

186. Brody, *supra* note 179, at 655; Gillick, *supra* note 175, at 207.

187. Linda Ganzini et al., *Nurses' Experiences with Hospice Patients who Refuse Food and Fluids to Hasten Death*, 349 *NEW ENG. J. MED.* 359, 363 (2003).

188. Robert M. McCann, M.D. et al., *Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration*, 272 *J. AM. MED. ASS'N* 1263, 1265 (1994).

supporters of such legislation think that feeding is different from other forms of medical treatment and that it is, as Pope John Paul II stated, “basic care” that should only rarely be withdrawn.¹⁸⁹ This concern signals perhaps the deepest division in the apparent prior consensus of end-of-life law; it is the issue most unsettled by the Schiavo controversy.

The characterization of tube feeding as “basic care” contrasts it with “extraordinary” or “artificial” interventions or “medical treatment” that individuals have a right to refuse. As the law in this area has evolved, tube feeding¹⁹⁰ has widely become viewed as “artificial” and as “medical treatment” in both court opinions¹⁹¹ and in state statutes,¹⁹² whereas the distinction between extraordinary and ordinary care has largely faded in importance. Legal decisions and commentary that have explained why such feedings are properly understood as medical treatment focus on the following characteristics of such feedings: the invasiveness of the procedure, especially the insertion of tubes that requires surgery, the inherent risks and side effects, the need for special personnel and training, special nutritional formulations, and coverage by insurance.¹⁹³ Some of the cases that uphold the right to withhold or

189. Nelson, *supra* note 157, at 156.

190. Tube feeding includes feeding by nasogastric tubes (inserted into the esophagus through the nose), gastrostomy tubes (tubes surgically placed into the stomach), jejunostomy tubes (tubes surgically placed in the small intestine), and intravenous infusions (less commonly used because of the difficulty of providing sufficient nutrition for the long-term patient). MEISEL & CERMENARA, *supra* note 3, § 6.03[G][1]. For patients in a permanent vegetative state, the percutaneous endoscopic gastrostomy (PEG) tube is the most common. JENNETT, *supra* note 1, at 88. The PEG tube procedure is minimally invasive, requiring “only two small incisions into the abdominal wall,” and has a low complication rate. Orentlicher & Callahan, *supra* note 42, at 391.

191. *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261, 288–89 (1990) (O’Connor, J., concurring).

192. See, e.g., VA. CODE ANN. § 54.1-2982 (2005) (including artificial nutrition and hydration in the definition of life-prolonging procedures that may be withheld or withdrawn by a surrogate decision-maker under VA. CODE ANN. § 54.1-2986).

193. *Cruzan*, 497 U.S. at 288–289 (1990) (O’Connor, J., concurring); *In re Conroy*, 486 A.2d 1209, 1226 (N.J. 1985)

[A]rtificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions are significantly different from bottle-feeding or spoon-feeding they are medical procedures with inherent risks and possible side effects, instituted by skilled health-care providers to compensate for impaired physical functioning. Analytically, artificial feeding by means of a nasogastric tube or intravenous infusion can be seen as equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own. . . . Furthermore, while nasogastric feeding and other medical procedures to ensure nutrition and hydration are usually well tolerated, they are not free from risks or burdens; they have complications that are sometimes serious and distressing to the patient.

Id.

withdraw artificial nutrition and hydration define it at least in part by reference to what it is presumably *not*, which is feeding by hand.¹⁹⁴ For example, in the Illinois case of *In re Estate of Longeway*, the court stated that there was agreement among states that allow the withholding of artificial nutrition and hydration that such feeding is “medical treatment and therefore analytically distinguishable from spoon-feeding or bottle feeding.”¹⁹⁵

The assumption of the court in *In re Estate of Longeway*, then, is that though patients have a right to refuse medical treatment, and thus tube feeding, they do not have a right to refuse feeding by hand.¹⁹⁶ Yet it is not at all clear that this is a valid assumption, and further examination of the issue of hand feeding, as it arose in the *Schiavo* case, may reveal certain insights into how we should view tube feeding, and in particular how we should view the argument that tube feeding is “basic care.”

The guardian ad litem appointed under Terri’s Law to make recommendations to Florida Governor Jeb Bush and the court recommended that Terri Schiavo be given swallowing tests and swallowing therapy.¹⁹⁷ The implication of this recommendation was that if Terri Schiavo could swallow and therefore take food by mouth, the issue of the feeding tube’s removal would be rendered moot. The feeding tube could then have been removed in accordance with Terri’s proven wishes to withhold medical treatment in such circumstances (as Florida law provides and as Michael Schiavo requested) *and* she could have continued living (as her parents wished). The dispute between Michael Schiavo and the Schindlers would be resolved.¹⁹⁸

Yet even if Terri Schiavo could have been fed by mouth, which she could not,¹⁹⁹ the controversy would have been no closer to resolution;

194. See, e.g., *In re Estate of Longeway*, 549 N.E.2d 292, 296 (Ill. 1989).

195. *Id.* Likewise, some state statutes clearly define artificial nutrition and hydration as that provided through means other than by mouth, such as through tubes, catheters, or needles.

196. *Id.*

197. WOLFSON REPORT, *supra* note 14, at 29–36 (explaining swallowing tests and recommending they be performed).

198. In fact, the guardian ad litem, Jay Wolfson, attempted to mediate this solution between Michael Schiavo and the Schindlers, but according to his report, those efforts were ultimately unsuccessful. WOLFSON REPORT, *supra* note 14, at 34, 39–40.

199. In the early years of her condition, when her husband Michael Schiavo aggressively pursued various therapies for her, Terri underwent swallowing tests and swallowing therapy; they were unsuccessful. WOLFSON REPORT, *supra* note 14, at 29. The circuit court with jurisdiction over Terri’s case declined to follow the guardian ad litem’s recommendation, as petitioned by the Schindlers, because Terri had previously undergone and failed such tests and because Dr. Wolfson’s recommendation was only to perform the swallowing tests if the parties agreed to be bound by the results. *In re Schiavo*, No. 90-2908GD-003 (Fla. Cir. Ct. Mar. 9, 2005) (order denying Schindlers’ petition). The court had denied a similar petition in 2000. *In re Schiavo*, No.

instead, we would have had before us another set of difficult questions to confront, namely, does a person have a right to refuse food by mouth? Does that right exist for people who have become incompetent? If so, how can that right be exercised? Are there any limitations on the right?

Some may argue that, in some cases, hand feeding is “artificial” and “medical treatment” for the same reasons that tube feeding is so. For example, in a case such as Terri Schiavo’s, hand feeding basically would have required the careful forcing of food down her throat, if her body could have been made to swallow reflexively. It would have been invasive, carried the inherent risk of aspiration pneumonia, required either special personnel or special training of caregivers, required special nutritional formulations, and would likely have been covered by insurance.²⁰⁰ It would not have resembled the more typical image of hand feeding, as when a bowl of chicken soup is spoon-fed to an ailing patient who is able to open his mouth to receive it.

The answer to the question of how to consider feeding by hand is not to be found, however, in likening it or distinguishing it from medical treatment or tube feeding. The basis for the constitutional, common law, and moral right to refuse tube feeding is not that it is medical treatment, but that tube feeding against the patient’s will is an intrusion into the bodily integrity of the individual.²⁰¹ Medical treatment given without patient consent is a battery, in common law terms, and a violation of one’s liberty interests in constitutional terms. The critical issue is not whether a particular “touching” or “intrusion” is “medical treatment” but whether it is unwanted, whether it is in a sense forced.²⁰²

90-2908GD-003 (Fla. Cir. Ct. Mar. 8, 2000).

200. See *In re Schiavo*, No. 90-2908GD-003 (Fla. Cir. Ct. Mar. 8, 2000) (order denying Schindlers’ petition). The order relates the testimony of Dr. Barnhill on the issue of whether Terri Schiavo could be fed by hand:

Dr. Barnhill testified that in his opinion attempting oral nutrition would result in aspiration with insufficient nutrition passing to the stomach to maintain her, thereby prolonging her death, if the feeding tube were withdrawn. He testified that such aspiration would lead to infection, fever, cough and ultimately pneumonia. This would require suctioning which likely would be fatal.

Id.

201. See *e.g.*, *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 287–89 (1990) (O’Connor, J., concurring) (“As the Court notes, the liberty interest in refusing medical treatment flows from decisions involving the State’s invasions into the body.”).

202. In *Cruzan*, the Supreme Court stated that “[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.” *Id.* at 278. In support of this inference, the court invoked *Jacobson v. Massachusetts*, which did not deal with medical treatment per se, but with government-imposed vaccinations. *Id.* at 278–79 (citing *Jacobson v. Massachusetts*, 197 U.S. 11, 24–30 (1905)). The Court also referred to cases analyzing searches and seizures that were thought to implicate

But if that is so, then unwanted hand feeding can also constitute an intrusion of bodily integrity and thus can be rejected by a competent patient. And if a competent patient can reject it, then an incompetent patient can also reject it, through his or her proxy or by advance directive.

There may be reasons to treat hand feeding differently from tube feeding, but it is difficult to describe any such reasons under our current constitutional standards for refusing unwanted treatment. At the same time, the thought of not attempting to hand feed an elderly patient with dementia is disturbing in ways that not placing a feeding tube in her stomach is not—even if both forms of treatment were clearly rejected in a duly executed living will. Why is this so? Some possible explanations may be: (1) there are limits on what may be asked of caregivers—just as we insist that caregivers be allowed to preserve the hygiene of the patient and her surroundings, we might insist that caregivers be allowed to offer basic sustenance in the form of hand feeding; (2) hand feeding might be experienced as comfort care by the patient in ways that tube feeding is not, either in the social relationship established through the process of hand feeding or through the pleasurable sensation of taking in food; (3) a patient may indicate that she desires hand feeding by appearing interested in food, by opening her mouth, and so on, so that we might say that these present actions trump her earlier declaration or we might say that she is not presently incapable of making the decision to consume food and so her advance directive is not operative on that point.

Of these three concerns, only the first might have been operative in Terri Schiavo's case, because even if she had been a candidate for hand feeding, she could neither experience the intake of food nor indicate a desire for it. That would leave only concern for her caregivers to weigh against her desire (as expressed by her proxy) not to continue living in her present condition. As between the two, respect for her autonomy

substantial liberty interests. *Id.* (citing *Breithaupt v. Abram*, 352 U.S. 432, 439 (1957)). In fact, the Court's discussion of the issue of the existence of a constitutional right to avoid unwanted medical treatment begins with the statement, "At common law, even the touching of one person by another without consent and without legal justification was a battery." *Id.* at 269. The Court quotes the 1891 case of *Union Pacific Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891), for the proposition that "[n]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." *Id.* at 269. It is this "notion of bodily integrity," the Court tells us, that "has been embodied in the requirement that informed consent is generally required for medical treatment." *Id.* The Court further quotes Justice Cardozo's famous statement from *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 129–30 (1914), that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body." *Id.* at 269.

should be sufficient to outweigh the interests of her caregivers. I would conclude, then, that even if Terri Schiavo could have been fed by mouth, that she should not have been. If her wish would be not to continue living in a permanent vegetative state, and thus to reject treatment that prolonged her life in that state, then her wish should not be overridden by society's and her caregivers' feelings of their duties to feed her.

Now what, if anything, does the consideration of the issue of hand feeding tell us that we can apply to tube feeding? Most immediately, it reveals the inadequacy of labeling feeding as "basic care" and assuming that that label answers questions about when and whether it must be provided or can be refused. Whether or not tube feeding is "medical care" or "basic care" is not really the question at all, because hand feeding falls rather neatly into the "basic care" box and yet it is not clear that hand feeding cannot be refused. In fact, it probably can be, at least in some situations, such as a permanent vegetative state.

Further consideration of the issue of feeding, both by tube and by hand, is necessary, especially after the *Schiavo* case's revelation of the lack of national consensus on the issue of feeding generally. First, we need to unpack what "care" means rather than categorize different forms of treatment as medical or basic care. In this regard, attention should be paid not only to the ends achieved through the provision of care (such as prolongation of life), but to how the individual receives or perceives the treatment that is given—whether it is taken in as care or not. If feeding is not experienced as care by the recipient, then it would not appear to be any different from other forms of unwanted treatment rejected on the basis of the patient's former autonomy.

The possibility of rejecting hand feeding by advance directive may unravel our current understanding, some may say "myth," that the right to refuse treatment is based in bodily integrity rather than autonomy. If an individual does have, in certain situations at least, a right to refuse hand feeding, then he might be able to execute an advance directive that refused hand feeding and have that advance directive honored. But what is the advance directive really saying? It seems that it would be saying, "If I end up in condition x, I want to die," rather than saying, "I reject the intrusion of caregivers offering me food." If, as this example illustrates, the right to refuse treatment is based in autonomy rather than bodily integrity, then the right looks more like a "right to die," and the reasoning behind the Supreme Court's rejection of a constitutional right to physician-assisted suicide is more difficult to accept.

In the physician-assisted suicide case of *Washington v. Glucksberg*, the Court explained the *Cruzan* decision as, at most, standing for the

proposition that there was a right to refuse bodily intrusions, not a right to determine the circumstances of one's death.²⁰³ Accordingly, *Cruzan* provided little support for a right to assistance in hastening death. While the Constitution may protect a person's right to reject unwanted life-sustaining treatment (because such treatment would infringe on bodily integrity), it did not provide a person with a right to seek treatment that may hasten death (which would be based in autonomy).

But this reasoning is rendered questionable by consideration of the issue of hand feeding. If in unpacking the problem of hand feeding we realize that what a right to refuse unwanted treatment really furthers is a person's right to die, because it is life in the present condition that is rejected rather than burdensome or intrusive treatments, then the right does look like it is grounded as much or more in autonomy than bodily integrity. Recognizing the autonomy basis for the right to refuse treatment may require a reexamination of the question of a right to physician-assisted suicide,²⁰⁴ as well as provide impetus for recognition of other rights based in autonomy or self-determination.

IV. CONCLUSION

The law of end-of-life decision making is due for reexamination. The case of Terri Schiavo makes that abundantly clear. Crucial questions, however, remain unresolved: among them, the proper role of surrogate decision making and the amount of discretion allowed to surrogates; the rights of those who are severely brain damaged but not permanently vegetative to refuse life-sustaining treatment; and the permissibility of withdrawing nutrition and hydration as compared to other forms of treatment.

But it is not just Terri Schiavo's case that signals the need for reexamination. The reason it captured so much attention and concern can be explained in part by the unease that many people feel about how these decisions are made. It is also indicative of the growing vitalist movement in the country, although it is unclear whether that movement has actually been embraced by more people in recent years or has simply become more visible. The questions are complex and important; the answers the law provides will have profound and lasting effects on

203. *Washington v. Glucksberg*, 521 U.S. 702, 725–26 (1997).

204. Rejecting a constitutional right to physician-assisted suicide may still be appropriate, but the explanation for that rejection would need re-evaluation. See Lois Shepherd, *Looking Forward with the Right of Privacy*, 49 U. KAN. L. REV. 251, 281 (2001) (arguing that the Supreme Court's rejection of a constitutional right to physician assisted suicide is consistent with the Court's prior jurisprudence, but not simply because of the distinction between rights based in bodily integrity and those based in autonomy or self-determination).

people's lives. While the law is certainly ripe for reexamination, it is not due for hasty, reactionary revision. Changes to our law of end-of-life decision making must be preceded by careful, informed, and responsible inquiry.